

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

**LOK SABHA
UNSTARRED QUESTION No. 765
TO BE ANSWERED ON 7th FEBRUARY 2025**

DELAY IN RARE DISEASE PROGRAMME ROLL OUT

765. SHRI NAVASKANI K:

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

- (a) whether the Government had planned to rollout Rs. 974 crore programme in the year 2024 under the National Policy for Rare Diseases 2021;
- (b) if so, the details thereof;
- (c) whether it is a fact that the expected rollout has not happened so far;
- (d) if so, the reasons for such delays along with the steps taken/proposed to be taken by the Government to expedite its implementation; and
- (e) the manner in which the Government plans to mitigate the adverse impact of delays on treatment of rare disease patients including those with Lysosomal Storage Disorders which may affect their health and survival prospects?

ANSWER

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

(a) to (e) Health is a State subject, therefore the primary responsibility of providing healthcare services is that of the respective State Governments. However, to mitigate the challenges posed by rare diseases in India, the Ministry of Health and Family Welfare (MoHFW) notified the National Policy for Rare Diseases (NPRD) on 30.3.2021. Under the policy 63 categories of Rare Diseases are identified which are further divided into three groups. Lysosomal Storage Disorders (LSD) are group three disorders which include diseases such as the Gaucher, Pompe and Fabry diseases. Around 700 patients of LSDs are registered under NPRD at 12 CoEs (as on November 2024). Under NPRD, financial assistance upto Rs. 50 lakh per patient is provided for treatment of patients suffering from any of the 63 Rare Diseases identified under the policy. MoHFW provides funds to the Centres of Excellence (CoEs) for treatment of rare disease patients.
