

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

**LOK SABHA  
UNSTARRED QUESTION No. 5660  
TO BE ANSWERED ON 4<sup>th</sup> APRIL 2025**

**TREATMENT FOR RARE DISEASES**

**5660. SHRI VISHALDADA PRAKASHBAPU PATIL:**

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

- (a) whether the Government has allocated 143.19 crore to 12 Centers of Excellence (CoE) under the National Policy for Rare Diseases 2021 and if so, the details thereof;
- (b) whether only 100 out of the 577 eligible Lysosomal Storage Disorder patients are receiving treatment, if so, the reasons therefor along with the corrective steps taken/proposed by the Government in this regard;
- (c) whether patients with Hunter, Hurler, Pompe, and Fabry Diseases who have DCGI approved therapies with proven outcomes, are being excluded from treatment by CoEs and if so, the details thereof and the reasons therefor;
- (d) the current number of patients treated for each of the said condition; and
- (e) whether the Government has any plans to include more eligible patients in the treatment framework of the above mentioned diseases and if so, the details thereof?

**ANSWER**

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

- (a) The Government has allocated Rs. 191.87 crore to the designated Centers of Excellence (CoEs) for treatment of patients under the National Policy for Rare Diseases (NPRD), 2021. Year-wise allocation of funds for treatment is placed at **Annexure I**.
- (b) No
- (c) Hunter, Hurler, Fabry and Pompe diseases are not excluded from treatment under NPRD.

(d) Information regarding number of Lysosomal Storage Disorders (LSDs) patients who have received treatment under NPRD is placed at **Annexure II**.

(e) 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, National Policy for Rare Diseases (NPRD), 2021 facilitates financial assistance of up to Rs. 50 lakhs per patient for treatment of identified Rare Diseases through the 13 designated Centers of Excellence (CoEs). The treatment is provided based on the recommendation of the Institutional Rare Disease Committee of the CoEs subject to the guidelines made under the policy. Furthermore, for the FY 2025-26, a budget of Rs. 264 Cr. has been allocated for treatment of patients, reflecting an increase from the previous years' budget allocation.

## Annexure I

Year wise fund Allocation to CoEs for treatment of rare diseases under National Policy for Rare diseases (NPRD), 2021:

(In Crore INR)

<b>Financial Year</b>	<b>Funds Allocated</b>
2022-23	35.00
2023-24	74.00
2024-25	82.87
<b>Total</b>	<b>191.87</b>

**Annexure II**

Number of Lysosomal Storage Disorders (LSDs) patients who have received treatment under NPRD, 2021:

<b>S. No.</b>	<b>Type of LSDs under NPRD</b>	<b>Number of Patients</b>
1.	Gaucher's Disease	287
2.	Hurler Syndrome (MPS Type 1)	65
3.	Hunter Syndrome (MPS Type 2)	76
4.	Pompe Disease	64
5.	Fabry Disease	20
6.	MPS IVA	87
7.	MPS VI	25
8.	Cystinosis	33
9.	Wolman Disease	2
	<b>Total</b>	<b>659</b>