

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

**LOK SABHA  
UNSTARRED QUESTION No. 5587  
TO BE ANSWERED ON 27<sup>th</sup> MARCH 2026**

**DELAY IN NPRD ASSISTANCE**

**5587. DR. BYREDDY SHABARI:**

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

- (a) the mechanism in place to ensure timely follow-up, communication and guidance to patients after completing registration under the National Policy of Rare Diseases (NPRD) through nodal officers and Centres of Excellence (CoEs);
- (b) the details of representations received regarding delays in processing applications and lack of communication after registration and the action taken by the Government thereon; and
- (c) whether the Government proposes to establish additional Centres of Excellence for Rare Diseases so that patients do not have to travel long distances for consultation and treatment in the country, particularly in Andhra Pradesh and if so, the details thereof?

**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 diseases in India, the National Policy for Rare Diseases (NPRD), 2021 provides financial and medical assistance for treatment of patients suffering from identified rare diseases in the designated Centers of Excellence (CoEs). A dedicated Rare Disease Committee (RDC) has been constituted in each CoE with the Nodal Officer for Rare Diseases being the Member Secretary of the RDC. The Nodal Officer and the RDC are responsible for regular counselling, scheduling Out Patient Department (OPD) visits, monthly reviews and providing updates to ensure proper guidance to patients.
- (b) In case of representations received regarding delays in processing applications, the concerned CoEs are directed to comply with the extant guidelines of the NPRD.
- (c) The Government has been identifying more CoEs across the country to increase accessibility and availability of treatment. Since the inception of NPRD, the number of CoEs has increased from 8 to 15, including 2 CoEs in the North-east India so that the patients do not have to travel long distances for consultation and treatment. Centre for DNA Fingerprinting and Diagnostics (CDFD, Hyderabad), Centre for Human Genetics (CHG, Bengaluru) and Institute Of Child Health and Hospital for Children (ICH & HC, Chennai) are the CoEs which are in close proximity for catering patients from Andhra Pradesh.

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