

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

**LOK SABHA
UNSTARRED QUESTION No. 817
TO BE ANSWERED ON 7th FEBRUARY 2025**

AFFORDABLE MEDICINES FOR RARE DISEASES

817. DR. K SUDHAKAR:

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

- (a) whether the Government has noticed that there are a large number of rare diseases in the country for which patients are unable to afford medicines and if so, the details thereof;
- (b) the details of the steps taken/proposed to be taken by the Government to ensure that medicines for rare diseases are available at low cost for the affected persons;
- (c) the steps taken/proposed to be taken by the Government to increase the number of screening for genetically rare diseases for newborn children in the country;
- (d) whether any support is given to such families by the Government for purchase of medicines and if so, the details thereof;
- (e) whether there are any plans to introduce rare disease medicines and medicines for critical care such as cancer through Pradhan Mantri Jan Aushadi Kendras and if so, the details thereof; and
- (f) whether genetically rare and other rare diseases are provided adequate cover under the Pradhan Mantri Ayushman Bharat scheme and if so, the details thereof?

ANSWER

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE**

(SHRI PRATAPRAO JADHAV)

(a) to (f) To mitigate the challenges posed by rare diseases in India, the Government notified the National Policy for Rare Diseases (NPRD) on 30.3.2021. The policy covers various aspects viz. financial assistance for treatment of Rare Diseases through identified Centers of Excellence; preventive strategy encompassing awareness generation, premarital, post-marital, preconception and post conception screening; counselling programmes to prevent births of children with rare diseases; enabling access to affordable health care to patients of rare diseases etc. The details of NPRD and other related circulars are available at Ministry of Health & Family Welfare (MoHFW) website viz. <https://mohfw.gov.in>. Financial Assistance upto Rs. 50 lakhs per patient is provided to the Centre of Excellence (CoE) identified by the MoHFW for treatment of 63 Rare Diseases identified under the NPRD 2021.

With a view to ensure that medicines for rare diseases are available at low cost for the affected persons, Department of Revenue, Ministry of Finance provides full exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) on import of Drugs/Medicines or Food for Special Medical Purposes (FSMP) used for treatment of rare disease, for personal use or through CoEs. In addition, financial incentives to domestic manufacturers of various product categories including Orphan drugs are provided under Production Linked Incentive Scheme of Department of Pharmaceuticals.

National Policy for Rare Diseases (NPRD) and Pradhan Mantri Ayushman Bharat Scheme are two different schemes of the Government of India. At present, the medicines for Rare Diseases are provided by the CoEs as per the provisions of the policy.
