

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

**LOK SABHA
UNSTARRED QUESTION No. 806
TO BE ANSWERED ON 7th FEBRUARY 2025**

CLASSIFICATION OF RARE DISEASES

806. SHRI PUTTA MAHESH KUMAR:

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

- (a) the details of list of diseases classified as rare diseases across the country;
- (b) the list of research bodies/authorities proposed, under construction and presently functioning for the purposes of research on prevent and cure of rare diseases across the country, State/UT-wise especially in Andhra Pradesh;
- (c) whether the Government has undertaken any research work regarding the prevention and cure of rare diseases across the country;
- (d) if so, the details regarding the funding which was allocated and utilised for the purposes of such programmes/initiatives across the country during the last five years, State/UT-wise, especially in Andhra Pradesh; and
- (e) whether the Government has taken any steps to increase awareness regarding rare diseases in the country and if so, the details thereof?

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

(a) As per National Policy for Rare Diseases (NPRD), 2021, 63 diseases have been identified as Rare Diseases in the country. List of classified Rare Diseases are available at Health Ministry's website viz. <https://mohfw.gov.in>.

(b) to (d) As per the mandate of NPRD, 2021, Department of Health Research (DHR) has constituted a National Consortium for Research and Development on Therapeutics for Rare Diseases (NCRDTRD) to streamline the research activities in the country. The Indian Council of Medical Research (ICMR) under DHR has taken following initiatives for research & development on Rare diseases:

- i. ICMRs-extramural Program Task Force On Rare Disease with a total budget of Rs. 16,00,73,899/-
- ii. ICMR has initiated 19 projects on drug development under the Call "Therapeutics for rare diseases" for developing indigenous therapies for rare diseases, with a total budget of Rs.18,73,24,318/-
- iii. ICMR National Registry for Rare and other Inherited disorders (NRROID).

(e) To enhance awareness about rare diseases, Ministry of Health and Family Welfare, organize workshops, symposium, seminars etc. from time to time.