

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

**LOK SABHA  
UNSTARRED QUESTION NO. 2564  
TO BE ANSWERED ON 06<sup>TH</sup> MARCH, 2020**

**POLICY ON RARE DISEASES**

**2564. SHRI VINAYAK RAUT:  
SHRIMATI SAJDA AHMED:**

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

- (a) whether the Government is contemplating to include more diseases in the draft policy on rare diseases;
- (b) if so, the details thereof;
- (c) if not, the reasons therefor;
- (d) whether the Government is planning to set up centre for excellence for rare diseases, if so, the details thereof, State/UT-wise including West Bengal; and
- (e) if so, the details thereof?

**ANSWER  
THE MINISTER OF HEALTH AND FAMILY WELFARE  
(DR. HARSH VARDHAN)**

(a) to (e): Draft of the National Policy for Rare Diseases, 2020, has been placed on the website of the Ministry of Health and Family Welfare on 13.01.2020, inviting comments/suggestions from all the stakeholders. The draft policy has noted the limitation of lack of epidemiological data on rare diseases in India and, therefore, based on clinical experience of experts, identified and grouped rare diseases in three categories for the purpose of the policy. The draft policy also provides for setting up a National Registry for Rare Diseases at Indian Council of Medical Research (ICMR) with the objective of creating a database of various rare diseases to arrive at a definition of rare diseases best suited to the country. It further provides for notifying 8 selected Centres of Excellence to begin with at premier Government hospitals with facilities for treatment of rare diseases, including Institute of Post-Graduate Medical Education and Research, Kolkata.

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