

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

**LOK SABHA
UNSTARRED QUESTION NO.3970
TO BE ANSWERED ON 19TH March, 2021**

RARE DISEASES

3970. SHRI GNANATHIRAVIAM S.:

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

(a) whether the diseases affecting less than one in 5000 people are categorized as rare diseases and the creation of social awareness about these diseases is the key to bettering the condition of patients;

(b) if so, the details thereof;

(c) whether the Government is aware that treatments for some of these rare disease are expensive, if so, the details thereof;

(d) whether the Government has noted that the beneficiaries of CGHS, health insurance and Government schemes are not able to get treatment for these rare diseases as they are not covered by these schemes, if so, the details thereof; and

(e) the steps taken by the Government in this regard?

ANSWER

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND
FAMILY WELFARE
(SHRI ASHWINI KUMAR CHOUBEY)**

(a) & (b): Globally, the definition of the rare disease varies across different countries. The data pertaining to rare disease is not available as of now. Hence, definition for rare diseases has not been finalized. However the Indian Council of Medical Research has initiated a rare disease registry, (ICMR Rare Disease registry, available at <http://bmi.icmr.org.in/irdr/index.php>).

(c) to (e): Specific treatments like gene therapy and antisense molecules etc are quite expensive. Government has formulated a National Policy for Treatment of Rare Diseases (NTPRD) in July, 2017, However, owing to implementation challenges, the said policy was kept in abeyance till the revised policy was issued or till further orders, whichever was earlier. An Expert Committee was constituted by Ministry of Health and Family Welfare in November 2018 to review the NPTRD, 2017 and draft revised NPTRD. Based on the report of the Expert Committee and with the approval of the competent authority, draft of the NPRD, 2020, has been finalized and placed on the website of the Ministry of Health and Family Welfare with a view to elicit comments/views of all the stakeholders, including States/UTs. The Draft policy provides for lowering the incidence of rare diseases based on integrated preventive strategy encompassing awareness generation and screening programmes and, within the constraints on resources and competing health care patients, enable access to affordable health care to patients of rare diseases. Further under CGHS, no separate guidelines are issued and treatments of beneficiaries suffering from such diseases are considered by competent Authority on a case to case basis, in consultation with experts in the field.