

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

**LOK SABHA
UNSTARRED QUESTION NO. 944
TO BE ANSWERED ON 08TH FEBRUARY, 2019**

RARE DISEASES

**944. SHRI L.R. SHIVARAME GOWDA:
SHRIMATI ANJU BALA:
SHRI TEJ PRATAP SINGH YADAV:**

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

- (a) whether according to the Indian Society for Clinical Research (ISCR) an estimated 70 million patients are living with life threatening rare diseases;
- (b) if so, the details thereof;
- (c) whether no comprehensive data is maintained on prevalence of rare diseases and the associated morbidity/mortality and if so, the reasons therefor;
- (d) whether Government has formulated a National Policy for Treatment of Rare Diseases and if so, the details thereof along with the funds sanctioned during each of the last three years, Statewise;
- (e) whether the construction work of new CGHS Dispensary in Patparganj, Delhi has been completed and if so, the details thereof along with probable date of its opening; and
- (f) if not, the reasons therefor?

ANSWER

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

(a) to (c): Government of India does not maintain any such data at central level. The Indian Council for Medical Research (ICMR) has finalized a project proposal to establish a National Registry for rare and other inherited disorders aimed at, among others, systematically generate data on prevalence of rare diseases.

(d): Government had formulated a National Policy for Treatment of Rare Diseases in the year 2017. However, the Government decided to review the Policy in the light of new information and updates available/received for its further improvement and effective implementation. Accordingly, the Policy has been kept in abeyance vide non-statutory Gazette Notification dated 18.12.2018, till the revised Policy is issued or until further orders, whichever is earlier. No funds were sanctioned under the National Policy for Treatment of Rare Diseases, 2017 during the currency of the said Policy.

(e) & (f): Construction work of new CGHS Wellness Centre in Patparganj, Delhi is almost complete except for some minor civil work and obtaining the completion certificate from the Municipal Corporation of Delhi.