

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

**LOK SABHA  
UNSTARRED QUESTION NO.5546  
TO BE ANSWERED ON 26<sup>TH</sup> JULY, 2019**

**GENETIC DISEASES**

**5546. DR. AMOL RAMSING KOLHE:  
DR. SUBHASH RAMRAO BHAMRE:  
SHRIMATI SUPRIYA SULE:  
SHRI KULDEEP RAI SHARMA:**

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

- (a) whether more than 50 lakh babies are born with genetic disease each year in India and the treatment is very expensive;
- (b) if so, whether the Government has conducted any detailed study in this regard and if so, the details and the outcome thereof;
- (c) whether the Government is aware that there are only few Government hospitals which provide specialized treatment for genetic diseases resulting in lot of suffering by genetic disorder patients, and if so, the reasons for not setting up specialized hospitals for treatment of genetic disorders in the country;
- (d) whether the Government has prepared any action plan to combat and cover such genetic diseases under the National Health Mission and set up a panel to frame a policy in this regard and if so, the details thereof and if not, the reasons therefor; and
- (e) whether the Government has set up any corpus fund for providing free treatment for genetic diseases and if so, the details thereof?

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

(a) to (e): There is no centralised information available regarding prevalence of genetic diseases in India. Indian Council of Medical Research (ICMR) has recently initiated steps to set up rare disease registry which will include most of genetic diseases.

Public health and hospitals being a State subject, it is the responsibility of State Government to set up hospitals to treat different kinds of disease conditions including genetic diseases.

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Government had formulated a National Policy for Treatment of Rare Diseases in the year 2017. However, the Government decided to review the Policy due to implementation challenges and 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.

Pending revision of the National Policy, under the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN), a component for treatment of rare disease has been included w.e.f. 01.01.2019 for providing one-time financial assistance to patients belonging to families living below threshold poverty line for treatment of identified Rare Diseases in Government hospitals. An amount of Rs.100 crore has been allocated for Rare Disease component of Umbrella Scheme of Rashtriya Arogya Nidhi during 2019-20.

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