

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

**LOK SABHA  
UNSTARRED QUESTION NO.3210  
TO BE ANSWERED ON 6<sup>TH</sup> DECEMBER, 2019**

**RARE GENETIC DISEASES**

**3210. SHRI SUDHAKAR TUKARAM SHRANGARE:**

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

- (a) whether the Government has formulated any National Policy for treatment of patients suffering from rare genetic diseases;
- (b) if so, the details thereof and if not, the reasons therefor; and
- (c) the steps taken by the Government for creating a dedicated fund for treatment of such patients?

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

(a) to (c): 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.

In the meanwhile, under the Umbrella Scheme of Rashtriya Arogya Nidhi, a component of rare disease has been included w.e.f. 01.01.2019 for providing one-time financial assistance upto Rs.15 lakh to patients belonging to families living below threshold poverty line for treatment of identified Rare Diseases amenable to one-time treatment 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.