

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

**LOK SABHA  
STARRED QUESTION NO.355  
TO BE ANSWERED ON THE 4<sup>TH</sup> JANUARY, 2019  
TREATMENT OF RARE DISEASES**

**\*355. SHRIMATI P.K. SREEMATHI TEACHER:**

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

(a) whether the Government has taken back the scheme/policy for Treatment of Rare Diseases; and

(b) if so, the details thereof and the reasons therefor?

**ANSWER  
THE MINISTER OF HEALTH AND FAMILY WELFARE  
(SHRI JAGAT PRAKASH NADDA)**

(a) & (b) : A Statement is laid on the Table of the House.

**STATEMENT REFERRED TO IN REPLY TO LOK SABHA  
STARRED QUESTION NO.355\* FOR 4<sup>TH</sup> JANUARY, 2019**

**(a) & (b):** The Central Government has decided to review the Policy in the light of new information and updates available/received for improvement and effective implementation. The Central Government has notified and informed the public at large that the said National Policy for Treatment of Rare Diseases, 2017, shall be kept in abeyance till the revised Policy is issued by the Central Government or till further orders, whichever is earlier. An Expert Committee has been constituted to revise the Policy.

Therefore, ad-interim, the Standing Finance Committee has approved a proposal for adding a sub-component under the Umbrella Scheme of Rashtriya Arogya Nidhi(RAN) for provision of one-time financial assistance to those below threshold poverty line for specified rare diseases which require one-time treatment.

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