

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

**RAJYA SABHA
UNSTARRED QUESTION NO.2163
TO BE ANSWERED ON 1ST JANUARY, 2019**

NATIONAL POLICY FOR TREATMENT OF RARE DISEASES

2163. SHRI SUSHIL KUMAR GUPTA:

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

- (a) whether it is a fact that several children suffering from rare diseases have succumbed to death while the Ministry is struggling with scarcity of funds for implementing the National Policy for Treatment of Rare Diseases;
- (b) whether the Ministry has sent any request to the Ministry of Finance for providing funds for implementation of this Policy under the Rashtriya Arogya Nidhi;
- (c) if so, the response of the Finance Ministry thereto;
- (d) whether Government has set up any technical committees and rare diseases cells for treatment of patients under this policy; and
- (e) if so, the details thereof?

ANSWER

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

- (a): Public Health and Hospitals is a state subject and it is the primary responsibility of the State Governments to address the healthcare needs of its population. No such information has been received from State Governments.
- (b) &(c): The Standing Finance Committee of the Ministry of Health and Family Welfare, comprising of Ministry of Finance, has approved a proposal for adding a sub-component under the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN) for provision of financial assistance for specified rare diseases which require one-time treatment.
- (d) & (e): The Central Government had set up a Rare Diseases Cell and a Central Technical Committee(CTC) as per the provisions of the erstwhile National Policy for Treatment of Rare Diseases 2017. Some State Governments namely, Delhi, Karnataka, Punjab, Gujarat, Jharkhand and Tamil Nadu had also reported to have constituted State Technical Committees.

.....