

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

**LOK SABHA
UNSTARRED QUESTION NO. 2906
TO BE ANSWERED ON 28TH DECEMBER, 2018**

TREATMENT OF RARE DISEASES

**2906. SHRI SUNIL KUMAR SINGH:
SHRI NAGAR RODMAL:
SHRIMATI SANTOSH AHLAWAT:**

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

(a) whether the Government has formulated a National Policy to provide financial assistance for Treatment of Rare Diseases and if so, the details thereof and the number of patients who got benefited through it, State/UT-wise including Jharkhand;

(b) whether it is a fact that there is scarcity of funds for the treatment of rare diseases and if so, the details thereof along with the details of funds made available for the treatment of rare diseases; and

(c) whether the Government has got any request in this regard and if so, the details thereof, State/UT-wise including Jharkhand along with action taken thereon?

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

(a) to (c): The Ministry of Health and Family Welfare had formulated a National Policy for Treatment of Rare Diseases in India in the year 2017. Subsequently it was decided to review the said Policy in the light of new information and updates for its further improvement and effective implementation. A Gazette Notification keeping the said Policy in abeyance till the revised Policy is issued by the Central Government has also been issued on 18.12.2018.

A total of 185 cases were referred to the Central Technical Committee for its decision which were kept pending in view of the CTC to formulate guidelines. Meanwhile, since a decision was taken to keep the Policy in abeyance, no funds to any patient were released. However, to comply with the directions of Hon'ble High Courts, funds for the treatment of 2 patients from Delhi and 1 each from Jharkhand and Maharashtra were released under the Rashtriya Arogya Nidhi., the details of which are annexed.

Annexure

Details of funds released to the patients of Rare Diseases under the Rashtriya Arogya Nidhi.

Name of the Patient	Funds released	Remarks
Baby Arshi, Delhi	Rs.10 lakhs	As per Delhi High Court order dated 31.8.2018
Master Ubed, Delhi	Rs.10 lakhs	As per Delhi High Court order dated 31.8.2018
Master Shaurya Singh, Ranchi	Rs. 10 lakhs	As per Jharkhand High Court order dated 8.2.2018
Mr. Chaitanya P Awathere, Nagpur	Rs.10 lakhs	As per Nagpur High Court order dated 8.1.2018