

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

**LOK SABHA
UNSTARRED QUESTION NO.3139
TO BE ANSWERED ON 6TH DECEMBER, 2019**

CASES OF PRADER-WILLI SYNDROME

3139. SHRI ARJUN SINGH:

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

- (a) the number of cases of Prader-Willi Syndrome reported in India;
- (b) the steps taken by the Government to provide treatment to the children afflicted by this disease;
- (c) whether there are any Group Homes or similar facilities to provide specialized care and supervision to those suffering by this disease; and
- (d) if so, the details thereof?

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

(a) to (d): Information regarding number of cases of Prader-Willi Syndrome is not maintained centrally.

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, a component for treatment of specified rare diseases, amenable to one time treatment, has been included under the Umbrella Scheme of Rashtriya Arogya Nidhi, for providing one-time financial assistance upto Rs.15 lakh to patients belonging to families living below threshold poverty line and taking treatment in Government Hospitals. Prader-Willi Syndrome is not covered in the list of specified rare diseases for assistance under the Umbrella Scheme of Rashtriya Arogya Nidhi.