

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

**LOK SABHA
UNSTARRED QUESTION No.3447
TO BE ANSWERED ON 17th DECEMBER 2021**

**HIGH COST OF DRUGS FOR THE TREATMENT OF SPINAL MUSCULAR
ATROPHY**

**3447. SHRI FEROZE VARUN GANDHI:
SHRI HANUMAN BENIWAL:**

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

- (a) the total number of reported cases of spinal muscular atrophy in the country, State/UT-wise;
- (b) whether the Government is aware of the high cost of drugs for the treatment of spinal muscular atrophy particularly the injections used in its treatment and if so, the details thereof;
- (c) the customs duty, GST and other taxes levied on such drugs;
- (d) whether the Government has taken any steps to control the prices of SMA drugs, and if so, the details thereof; and
- (e) if not, whether the Government proposes to undertake such steps to make the medicine/injection more affordable or proposes to bear the high expenditure on medicine/injection for treatment of patients including children?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE
(DR. BHARATI PRAVIN PAWAR)**

- (a) ICMR has initiated a National Registry wherein epidemiological data is collected for Rare diseases and other inherited disorders. Data of a total of 4001 rare disease cases (storage disorders, small molecular inborn errors of metabolism, primary immune deficiency disorders, skeletal dysplasia, neuromuscular disorders, haemoglobinopathies and bleeding disorders) have been collected till 31st October, 2021. The number of patients of Spinal Muscular Atrophy enrolled in the registry portal is 295. Information specific to each State/UT is not maintained centrally.
- (b) & (c) As informed by the Department of Revenue, Ministry of Finance, for general imports, medicines used in the treatment of Spinal Muscular Atrophy attract Basic Custom Duty of 10% and IGST of 12%. However, individuals are allowed to import medicine for Spinal Muscular Atrophy without payment of Customs Duty and IGST (Nil Custom Duty and Nil IGST) if the following conditions are satisfied:

(i) the goods are imported by an individual for personal use;

(ii) it is certified in the Form as applicable, by the Director General or Deputy Director General or Assistant Director General, Health Services, New Delhi, Director of Health Services of the State Government or the District Medical Officer/Civil Surgeon of the district, in each individual case

(iii) the importer produces the said certificate to the Deputy Commissioner of Customs or the Assistant Commissioner of Customs, as the case may be, at the time of clearance or gives an undertaking to furnish the said certificate.

(d) &(e) In order to help the patients in terms of affordable medicines, Department of Pharmaceuticals has initiated the implementation of Production Linked Incentive Scheme for Pharmaceuticals. The Scheme provides for financial incentives to manufactures selected under the Scheme for domestic manufacturing of various product categories, which also include Orphan drugs. The Guidelines for the Scheme are available on the website of the Department of Pharmaceuticals under the tab ‘Schemes’.