

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

**LOK SABHA  
UNSTARRED QUESTION NO. 1714  
TO BE ANSWERED ON 11<sup>th</sup> February, 2022**

**SPINAL MUSCULAR ATROPHY**

**1714. SHRI PRADYUT BORDOLOI:**

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

(a) the number of children currently diagnosed with Spinal Muscular Atrophy (SMA) in the country gender/age-wise along with the rate of prevalence of SMA in India;

(b) whether the Government has initiated measures to spread awareness about SMA and ensure sound detection and diagnosis, if so, the details thereof;

(c) whether the Government intends to ensure affordability of Risdiplam/Evrysdi, the life-saving drug for SMA, given its exorbitant pricing, if so, details thereof;

(d) whether the Government intends to initiate dialogue with manufacturers of Risdiplam/Evrysdi for affordable access in India, if so, the details thereof; and

(e) whether the Government has taken action to address the aspects of care for patients with SMA during the pandemic for being at increased risk of manifesting severe COVID symptoms and if so, the details thereof?

**ANSWER**

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

(a) As per data available on National Registry, 295 Spinal Muscular Atrophy cases have been reported. Of them, 188 (63.70%) are male and 107 (37.30 %) are female. Preliminary analysis of age distribution of the cases (N=295) are as follows: <1 year-140 (47.5%); 1 to <5 years- 91 (30.8%); 5 to <10 years-9(3.1%) and Not Known-46(15.6%).

(b) National Policy for Rare Diseases, 2021 has been finalized on 30.03.2021; circulated to all States/UTs, stakeholders and published on the website of Ministry of Health & Family Welfare. The Policy can be accessed at website-<https://main.mohfw.gov.in/documents/policy>.

(c) Department of Revenue, Ministry of Finance vide their Notification No. 46/2021-Customs dated 30.09.2021 gives full waiver of Basic Customs Duty (BCD) and IGST to drugs imported (personal use only) for treatment of SMA, thereby making the medicines for SMA more affordable.

(d) Department of Pharmaceuticals has initiated the implementation of Production Linked Incentive Scheme for Pharmaceuticals. The Scheme provides for financial incentives to manufacturers selected under the Scheme for domestic manufacturing of various product categories, which also include Orphan drugs.

(e) Ministry of Health and Family Welfare has issued various guidelines to address the aspects of care for patients with comorbidities during the pandemic of Covid-19.

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