

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

**LOK SABHA  
UNSTARRED QUESTION NO. 2851  
TO BE ANSWERED ON 12<sup>TH</sup> MARCH, 2021**

**SPINAL MUSCULAR ATROPHY**

**2851. SHRI VISHNU DATT SHARMA:**

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

- (a) whether it is a fact that India has three lakh Pediatric patients suffering from Spinal Muscular Atrophy, if so, the details thereof;
- (b) whether the proposal to waive off custom duty on costly medicinal injections for the treatment of children with Spinal Muscular Atrophy has been implemented;
- (c) if so, the details thereof and the extent to which it is likely to benefit the children suffering from the above disease;
- (d) whether his Ministry has any scheme to provide assistance for such patients in view of higher treatment costs; and
- (e) if so, the details thereof and if not, the reasons therefor?

**ANSWER**

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

(a): Data pertaining to the epidemiology of spinal muscular atrophy is not available as of now. However, the Indian Council of Medical Research has started a rare disease registry, (ICMR rare diseases registry, available at <http://bmi/icmr.org.in/irdr/index.php>). Accordingly, the epidemiological data pertaining to spinal muscular atrophy may be available in future

(b): No.

(c): Not applicable

(d) & (e): Treatment modalities like assistive devices and physiotherapy are available at most tertiary care institutions in the country. Specific treatments like gene therapy and antisense oligonucleotides are quite expensive.

However, no separate rehabilitation mechanisms are available for spinal muscular atrophy patients. The rehabilitation facilities available at tertiary care institutions are being utilized for these patients also.