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

LOK SABHA
UNSTARRED QUESTION NO. 1112
TO BE ANSWERED ON 18TH SEPTEMBER, 2020

MUSCULAR DYSTROPHY PATIENTS

1112. SHRI DEVJI M. PATEL:

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

(a) the provision for treatment of Muscular Dystrophy patients in the country;

(b) the funds spent for the same, head/item-wise till 2019;

(c) whether Government has made any provision for providing facility for genetic test free of cost in order to diagnose the causes of disease in patients suffering from Muscular Dystrophy;

(d) if so, the details thereof and the number of patients who got their tests done in the last three years in the country; and

(e) the number of such patients died during the last three years and thereafter till date in the country, State wise including Rajasthan?

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

(a) to (e): Treatment modalities for muscular dystrophy patients inter alia include steroid therapy, use of assistive devices and vaccination for prevention and management of complications of muscular dystrophy. These facilities are available at most tertiary care institutions in the country. However, specific treatments of muscular dystrophy like exon skipping, ataluren therapy, etc are very expensive and drugs are to be imported. Tertiary care institutions also have facilities for genetic test to diagnose the causes of diseases in patients suffering from Muscular Dystrophy. These are available in Government institutions free of cost or highly subsidized for poor patients. No separate data is available for funds spent for treatment of Muscular Dystrophy, number of tests and number of deaths of Muscular Dystrophy patients in the country.

Government had formulated a National Policy for Treatment of Rare Diseases (NPTRD) in July, 2017. However, owing to implementation challenges, the said policy was kept in abeyance till the revised policy was issued or till further orders, whichever was earlier. An Expert Committee was constituted by Ministry of Health and Family Welfare in November, 2018 to review the NPTRD, 2017 and draft revised National Policy for Rare Diseases. Based on the

report of the Expert Committee and with the approval of the competent authority, draft of the National Policy for Rare Diseases, 2020, has been finalized and placed on the website of the Ministry of Health and Family Welfare with a view to elicit comments/views of all the stakeholders, including States/UTs. The draft policy provides for lowering the incidence of rare diseases based on integrated preventive strategy encompassing awareness generation and screening programmes and, within the constraints on resources and competing health care patients, enable access to affordable health care to patients of rare diseases.