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

LOK SABHA UNSTARRED QUESTION NO. 2075 TO BE ANSWERED ON 23RD SEPTEMBER, 2020

ASSISTANCE TO MUSCULAR DYSTROPHY PATIENTS

2075. SHRI DEVJI M. PATEL:

MS. PRATIMA BHOUMIK:

SHRI SUDHAKAR TUKARAM SHRANGARE:

SHRI SUMEDHANAND SARASWATI:

SHRI RANJEETSINGH HINDURAO NAIK NIMBALKAR:

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

- (a) whether the number of patients of Muscular Dystrophy is on the rise in the country;
- (b) if so, the details thereof along with the number of patients registered under Muscular Dystrophy, State/ UT-wise;
- (c) whether Government has any rehabilitation mechanism for muscular dystrophy patients separately, if so, the details thereof and if not, the reasons therefor; and
- (d) whether the Government has any scheme/ provision to provide financial assistance to the muscular dystrophy patients and 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) to (d): There is lack of epidemiological data on incidence and prevalence of rare diseases including Muscular Dystrophy. No separate data is available regarding number of patients of Muscular Dystrophy in the country.

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 rehabilitation mechanisms are available for muscular dystrophy patients. The rehabilitation facilities available in tertiary care institutions for all patients are being utilised for muscular dystrophy patients also.