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

LOK SABHA
UNSTARRED QUESTION No. 5592
TO BE ANSWERED ON 27th MARCH 2026

DUCHENNE MUSCULAR DYSTROPHY (DMD) IN CHILDREN

5592. SHRI DEEPENDER SINGH HOODA:

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

(a) whether the Government has data on the number of children who have died due to Duchenne Muscular Dystrophy (DMD) during the last five years, if so, the details thereof, year-wise and State/UT-wise and if not, the reasons therefor;

(b) the estimated number of children suffering from DMD in the country, State/UT-wise; and

(c) whether the Government has prepared any time-bound roadmap to address DMD in the country, including milestones such as the availability of affordable treatment and the establishment of treatment centres and if so, the details thereof?

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE
(SHRI PRATAPRAO JADHAV)

(a) and (b) As per the data obtained from the National Registry for Rare and Other Inherited Disorders (NRROID) maintained by the Indian Council of Medical Research (ICMR), since 2019, around 4749 Duchenne Muscular Dystrophy (DMD) patients have been enrolled in 23 centers across the country. A total of 184 DMD patients are reported as deceased in the Registry. State/UT-wise distribution of this data is placed at annexure.

(c) DMD is categorized as a rare disease under the National Policy for Rare Diseases (NPRD), 2021 framed by the Ministry of Health and Family Welfare. Health being a State subject, the primary responsibility of providing healthcare services is that of the State Governments. However, to mitigate the challenges posed by rare diseases in India, the policy provides financial and medical assistance for treatment of patients suffering from identified rare diseases in the designated Centers of Excellence (CoEs). Following measures have already been taken to address the DMD issue:

- The limit of financial assistance provided by NPRD for treatment of rare disease has increased from ₹20 lakhs to ₹50 lakhs per patient. Rare Disease Committee of the CoEs decides treatment and fund allocation after clinical examination on case-to-case basis.
- Since the inception of the NPRD, the number of CoEs has increased from 8 to 15 and the number of rare diseases covered under the policy has increased from 51 to 63.
- The Ministry of Finance provides exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) on most of the drugs, medicines and Food for Special Medical Purposes (FSMP), subject to extant rules.

- Some Made-in-India drugs have become available at 1/10th of the price of the imported Reference Listed Drug (RLD) as NITI Aayog constituted a Committee for 'Drugs and Dosage Forms for Rare Diseases: Engagement with Manufacturers' to fast track indigenous development and marketing of identified orphan drugs by engaging with domestic manufacturers.
- The Department of Pharmaceuticals has initiated implementation of 'Production Linked Incentive' scheme for pharmaceuticals which provides financial incentives to the manufacturers selected for domestic manufacturing of various product categories, including rare disease medicines.

Annexure

State/UT-wise number of DMD Patients enrolled in the NRROID since 2019

State/UTs	No. of patients
Uttar Pradesh	911
Karnataka	547
West Bengal	428
Tamil Nadu	342
Bihar	300
Delhi	286
Andhra Pradesh	255
Rajasthan	219
Madhya Pradesh	209
Telangana	201
Haryana	197
Kerala	153
Maharashtra	149
Punjab	147
Gujarat	77
Odisha	58
Jharkhand	51
Himachal Pradesh	44
Assam	42
Jammu Kashmir	33
Uttarakhand	31
Chhattisgarh	25
Tripura	15
Chandigarh	13
Puducherry	7
Ladakh	3
Manipur	3
Nagaland	2
Mizoram	1
Grand Total	**4749**

Source: National Registry for Rare and Other Inherited Disorders (NRROID) maintained by Indian Council of Medical Research.

State/UT-wise distribution of deceased DMD patients in the NRROID since 2019

State/UTs	**No. of patients**
Karnataka	77
West Bengal	25
Andhra Pradesh	24
Uttar Pradesh	11
Assam	7
Bihar	7
Tamil Nadu	5
Telangana	5
Haryana	4
Kerala	4
Maharashtra	4
Rajasthan	3
Punjab	2
Chhattisgarh	1
Delhi	1
Jharkhand	1
Madhya Pradesh	1
Odisha	1
Tripura	1
Total	**184**

Source: National Registry for Rare and Other Inherited Disorders (NRROID) maintained by Indian Council of Medical Research.