

## DUCHENNE MUSCULAR DYSTROPHY ON THE RISE IN STATE

**NIRUPA SAMPATH** @ Tiruchy

DUCHENNE Muscular Dystrophy (DMD), a rare genetic disorder, affects one in every 1,400 live male births across the State, three times higher than the global figure. The year 2020 has been assigned to identify and treat children suffering from DMD by the Molecular Diagnostics, Counselling Care and Research Centre (MDCRC), which conducted a door-to-door survey with the State Planning Commission.

"Globally one in 3,500 live male births suffers from DMD. In Tamil Nadu, it is much more common. Since 2011, 496 cases of DMD in consecutive male births in the same family have been diagnosed so far, which calls for immediate attention and awareness," said MDCRC director B R Lakshmi.

She added, "This day is dedicated to International Rare Disorder Day and DMD easily makes it to the list. Any disorder is considered rare when the numbers are one in 10,000 for a specific disorder. However, in the case of DMD, it is not rare but a neglected disorder even among doctors."

K Anbagazhan, a resident of Kulumani who lost his son a few years ago with DMD, said, "It is not only about awareness among the public, even doctors do not know how to diagnose the disorder. I was often told by doctors in the city to give up on treating my son as he would soon die. My daughter also suffers from DMD, which is rare among girls, however, I am doing my best to treat

her."

DMD is the most common of the nine types of muscular dystrophy. It is caused by the absence of dystrophin, a protein that helps keep muscle cells intact. The absence leads to progressive muscle degeneration and weakness among boys starting at roughly around the age of three. Mental agility is affected and physical disabilities increase with age until boys finally yield to the disorder and die in their late teens.

According to the MDCRC survey, current DMD cases in the central districts of the State are much higher than for the southern districts. Salem, Erode, Tiruchy, Nagapattinam, Tirunelveli and Coimbatore score the highest with Kanyakumari, Sivagangai, Krishnagiri and Ram-anathapuram showing the least.

Causes of the disorder can be genetic and non-genetic. Couples marrying within the

family have chances of having a child with DMD. "When women give birth to one child with DMD, there are higher chances of her eggs having a dystrophin gene mutation and passing it on to the next child. With timely treatment, it can be prevented. Unmarried women who may feel such cases exist in the family are advised to get tested," said Lakshmi.

MDCRC is the only centre in the State to provide molecular diagnosis, counselling for the patient and parents and to mothers to be free from guilt, multidisciplinary care and rehabilitation.



Even doctors do not have proper knowledge about the disorder. There are an ample number of patients in the city who are in dire need of the right treatment

A patient



### AGE GROUP

2-3 years, First stage

6-7 years, second stage

9-10 years, third stage

10-12 years, fourth stage

### SYMPTOMS

Frequent falls, Toe walking.

Difficulty in climbing stairs without support.

Difficulty in sitting up, Gowers Syndrome.

Losing ability to walk. Dependent on wheelchair.

SUVAJIT DEY