

State's first model rehabilitation centre for rare fatal genetic disorder coming up in Coimbatore

Staff Reporter

COIMBATORE: The first model rehabilitation centre for patients of 'Duchenne Muscular Dystrophy (DMD),' a rare incurable genetic disorder that fatally affects children as young as three years, is coming up in Coimbatore.

The State Government has approved Molecular Diagnostics, Counselling, Care and Research Centre (MDCRC), the only government recognised referral centre in Tamil Nadu for DMD, to establish this centre, where all treatment, drugs and even transport will be provided free of cost. The centre would be inaugurated on Saturday.

Addressing a press conference here on Wednesday,

B.R Lakshmi, Director of MDCRC, said that DMD was called an 'orphan disease' as it affected only a small percentage of the population and hence, very little resources were devoted to tackle it.

It was a degenerative disease that sets in by around three to five years.

The symptoms include the child falling down frequently, difficulty in arising from a seated position (Gower's syndrome) and slowly results in the child losing the ability to walk by ten to 15 years and finally, results in loss of life due to respiratory illness by 18 to 20 years.

There were 163 registered DMD patients in Coimbatore. This centre would provide integrated

comprehensive care including physiotherapy, yoga and medication. A library would also be set up.

The children would have to come twice a week. Physiotherapy would also be given to the mothers, who often have to carry the children, she said.

In a study commissioned by the National Rural Health Mission and Indian Council of Medical Research (ICMR), the MDCRC found the prevalence of DMD to be at least 2.3 times higher than global average of 1:3,500 in five Western districts.

The study, which covered nearly 14 lakh houses in Coimbatore, Tirupur, Dharmapuri, Salem and Erode, found the prevalence rate to be 1:1,400. A subsequent

survey in The Nilgiris, Karur and Namakkal also found similar prevalence rates, she said.

The key to tackling this disease was early identification. Through molecular diagnostics, she said that women could be identified if they are carriers and counselled accordingly. The MDCRC, which provided all services free of cost, is looking for support from philanthropists to scale up its services and reach more patients. It can be reached through

www.mdrcindia.org. While Tamil Nadu had around five model rehabilitation centres for patients with muscular dystrophy, of which there are 57 kinds, she said that this was the first one to focus exclusively on DMD.