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Muscular dystrophy registry soon

Karthik Madhavan

COIMBATORE: Parents, doctors, researchers and others concerned with muscular dystrophy (MD) will have something to cheer about, as a registry is in the making.

It is likely to come up at the Molecular Diagnostics, Counselling, Care and Research Centre (MDCRC) at Avinashilingam University, covering the southern and eastern parts of the country. This is important because MD, termed orphan disease, affects muscles that move the body and has no cure.

The data entered in the registry will have descriptive, analytical and preventive portions based on tests conducted on persons with MD, which then can be used for a

variety of purposes, says B.R. Lakshmi, Principal Investigator, MDCRC. "It will be of international standards."

The descriptive part will contain data of persons with MD, as presented by the referring doctors, analytical part will have their molecular and clinical tests results conducted at the MDCRC and preventive part will consist of details of those carrying defective genes. Explaining the details, she says as and when doctors refer MD persons to the MDCRC with a report, authorised persons examine the same and after consent from parents or caretakers carry out molecular diagnosis.

The diagnosis, which is done free of cost, is necessary to identify the reason for MD, and the data can be used for

preventive purposes as well as to aid on-going research.

Ms. Lakshmi explains: "For example, when the MDCRC comes to know that a woman is a carrier of the defective gene, she will be told about it because there is a 50 per cent chance that her offspring will either be another carrier or suffer MD. And this way preventive measure can be taken." "The data from the analysis will also aid research because when the nature of the defect in the gene is identified, research centres like MDCRC and pharmaceutical companies can work on it."

At present there are 1,200 entries in its registry and this is likely to go up once the Indian Council of Medical Research grants the 'referral centre' status to the MDCRC.

These entries contain data of MD persons mostly in Tamil Nadu and a few neighbouring states. Ms. Lakshmi says this will happen anytime soon and once it happens, doctors in southern and eastern parts of the country will be obliged to refer MD cases to MDCRC.

That apart, the Centre will also offer periodical clinical evaluation of MD persons and the progress they make will also be a part of the data entered into the registry. "This is important because the condition worsens with age. And the response to different methods can be noted," she points out. The Centre will also work on providing care for the affected children and among the community to create awareness on MD, she adds.