

Youth Convention

Ramakrishna Mission Vidhyalaya will organise a Youth Convention at Vidhyalaya Indoor Sports Hall at 5.15 a.m. onwards.

Workshop

Coimbatore Institute of Education will organise a workshop at 8.45 a.m.

DEC-3/12/2014

Only one centre to treat 'orphan disease'

December 3 is observed as International Day of People with Disability

R. Sairam

COIMBATORE: When the child began to experience frequent falls at the age of four, the father, a government employee, consulted the family physician who prescribed vitamins to gain strength and pain killers.

However, medicines failed to work and he took the child to a Siddha doctor, who prescribed oil massages. Six months later, the child's condition worsened. The father consulted several other doctors but none could identify the problem.

Duchenne Muscular Dystrophy

After several months, he consulted the Molecular Diagnostics, Counselling, Care and Research Centre (MDCRC) here, where the diagnosis revealed the child to be suffering from 'Duchenne Muscular Dystrophy (DMD)', a rare and incurable genetic neuromuscular disorder that fatally affects children as young as three years.

Even though the parent in



Children with Duchenne Muscular Dystrophy who are undergoing treatment at the Molecular Diagnostics, Counselling, Care and Research Centre in Coimbatore. - PHOTO: SPECIAL ARRANGEMENT

this case was educated and had economic means, they were unable to identify the disease for a long time.

This was due to the low awareness level about DMD as it affects only a minuscule section of the population and hence, little resources are devoted to tackling it, says B.R. Lakshmi, Director of MDCRC, the only govern-

ment recognised referral centre in Tamil Nadu for DMD. Hence, it is often known as 'the orphan disease' since it is neglected.

While the parent hails from Erode, the sole rehabilitation centre in Tamil Nadu, one of the States with advanced healthcare, devoted exclusively for DMD patients exists in Coimbatore thereby

posing difficulties in undergoing rehabilitation.

As yet another International Day of People with Disability, observed annually on December 3, approaches, rapid strides have been made towards recognising the rights of persons with disabilities. Yet there are a few disabilities that are receiving scant attention, with DMD being foremost among them, says Dr. Lakshmi.

Of the six centres for treating muscular dystrophy in Tamil Nadu, there is only one for DMD patients, she says.

The DMD is a progressive disorder that's characterised by loss of muscle function, first in the lower limbs followed by upper limbs and finally internal organs, which will lead to a fatal respiratory failure.

It causes stiffness in bone joints and deformities, respiratory problems and other cardiac complications.

In a study commissioned by the National Rural Health Mission and Indian Council of Medical Research (ICMR), the MDCRC found the preva-

lence of DMD to be at least times higher than global average of 1:3,500 in eight Western districts.

While many forms of disability have received attention in recent years, she says more needs to be done for patients of DMD.

Even within the house, patients need help to move from bed/wheelchair and carry out daily activities. Financial burden is high due to the constant care required for the patients.

Most often, one parent stays at home to take care of affected child.

Untreated DMD children usually die in their late teens or early twenties due to respiratory or cardiac failure.

"The rate of correct clinical diagnosis is poor for DMD due to the rarity of the disorder and the inexperience of the physicians," she says.

While the disease was curable, it can be prevented. During pregnancy, prenatal diagnostic techniques can be carried out to identify whether the foetus is affected by the disorder, says Dr. Lakshmi.