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World Duchenne Awareness Day observed



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The First World Duchenne Awareness Day was observed at MDCRC here on Sunday.

Duchenne Muscular Dystrophy is a devastating, life threatening genetic neuromuscular disorder affecting boys. Concerted and focused efforts are required to prevent this disorder in our society. The vast majority of Duchenne patients are boys and young men who progressively lose their physical functions before they inevitably die of this cruel disease. Duchenne Muscular Dystrophy is one of the most common fatal genetic disorders which affects on average 1 in every 3500 newborn boys, with very few girls suffering from the disease.

Boys affected with Duchenne first lose the ability to walk during their childhood days and as they grow into adolescents they also lose the ability to use their arms, carry out everyday activities such as writing or feeding themselves, and their ability to breathe deteriorates as well. As they grow into young men they finally succumb to the disease and die due to respiratory problems or

heart failure. Majority do not reach adulthood at all.

As the disorder does not have cure till date, MDCRC has embarked its collaboration with The Arya Vaidya Pharmacy (AVP), to understand the therapeutic advantage that Ayurveda can offer under the able leadership of Dr. K.G. Raveen dran & team. The response to this initiative is encouraging and promises to offer better quality of life to the affected children.

In commemoration of World Duchenne Awareness Day, MDCRC had organized a free Duchenne Muscular Dystrophy screening camp on 7th September 2014, at Kurinji Hospital, Nava India, Coimbatore. Before the inauguration of the camp, there was a short program to understand the significance of this day. Coimbatore District collector, Mrs. Archana Patnaik, IAS delivered a special address at the gathering after hoisting the National flag at Kurinji. Duchenne awareness day logo was transformed into a flag at MDCRC and hoisted by Dr. KC Ramaswami, the Chairman of Kurinji Hospital, Coimbatore.

On this occasion,

MDCRC had relaunched its website which was inaugurated by Dr. PR Krishnakumarji, the Managing Director, Arya Vaidya Pharmacy, Coimbatore who is also a board of trustee at MDCRC. In continuation with the relaunch of the website, Dr. Lakshmi briefed the gathering about the significance of the World Duchenne Awareness Day in which she emphasized the various services offered and the ways to prevent his lethal genetic disorder. Following this was the special address of the collector where she mentioned that this orphan disorder was a totally new term for her until in 2011 when she had come across the MDCRC team in Nilgiris doing survey on the identification and prevention of this disorder. Madam was highly impressed with the kind of work being done by MDCRC. By seeing some of the children affected with Duchenne, she expressed that she had no words to say about the optimistic attitude and the enthusiasm the little children had. Rotary Club of Coimbatore West had donated 3 wheel chairs to the desperately in need

children which was given away by Dr. KC Ramaswami, chairman, Kurinji Hospital, Coimbatore. It was interesting to hear the voice of parents where a mother shared her views on this event to the gathering. Last but not the least, was the thank you note by Dr. Nandakumar, pediatric neurologist at MDCRC.

A free camp where more than 15 suspected children were brought in for clinical diagnosis was also inaugurated on the occasion. The highlight of the awareness program was the rally which was conducted from collector bungalow, race course. Around 140 student volunteers from Krishnammal college for Women participated in the rally along with few clinicians and Rotarians. The rally was flagged off by collector madam. Archana Patnaik motivated the student volunteers to participate more in the awareness programs.

It was a gala event with the children feeling it was their day with the collector madam and the other dignitaries addressing them and making them feel very important.