DART Lab's Duchenne Muscular Dystrophy Awareness Week

Highlights

- Duchenne muscular dystrophy (DMD) an inherited disease involves muscle weakness
- Duchenne awareness day held each year on the 7th September aims at raising awareness about the disorder
- Dystrophy Annihilation Research Trust (DART) is the first lab in India focusing on DMD research

Dystrophy Annihilation Research Trust (DART) is the first lab in India focusing on DMD research. The lab is working on reversing the absence of dystrophin at the genetic level through exon skipping. RS Anand, President and founder has been tirelessly working for this cause since his 15-year-old son Karanveer is affected by DMD. In recognition for DART's effort, the lab won PTC Therapeutics' 2016 STRIVE award for working towards innovative solutions to manage DMD.

To commemorate Duchenne Awareness Day held each year on 7th September, DART lab held a series of events beginning 4th September with an awareness marathon and ending on 11th September with the inauguration of a physiotherapy and evaluation centre, art and music gallery and a bake sale. Duchenne Awareness Day aims at raising public awareness about this disorder and spreading knowledge. This year's theme focused on early diagnosis which goes a long way in beginning early treatment and physiotherapy programs.

The first event kick-started to mark the awareness week was the walkathon organized in association with the Delhi Public School (DPS), North Bangalore. The walkathon took place at the Central Library, Cubbon Park on Sunday 4th September. The principal from DPS and several children took part to raise public awareness about the condition. Volunteers from CARE (Charlie's Animal Rescue Centre) also participated with their canine friends.

The culmination event for the awareness week was held on 11th September at the DART India lab in Bangalore. This big event had a series of activities centered on the health and well-being of the children with DMD. One of the main attractions was the art gallery showcasing the artworks of the children. The artistic

and expressive talent of the children was visible in the boards displaying the colorful, attractive pieces.

This big day was inaugurated by lighting the lamp with researchers, collaborators, friends and well-wishers like Prof. Upendra Nongthomba from the Indian Institute of Science, Prof. Vijay Chandru, Chairman, Strand Life Sciences and others. A major milestone for DART lab was the inauguration of the physiotherapy unit which is important for the children for rehabilitation and improvement of muscle tone. The unit also has special equipment for checking out respiratory strength and breathing capacity.

The attraction that excited all the children and adults alike was the bake sale with its yummy display of goodies like custard, mousse, cupcakes and pastries. This was inaugurated by children like Karanveer and Daivik amidst much gusto and enthusiasm.

To add a dash of rhyme and rhythm to the event, there was the music corner with Karanveer and his rock band. This music corner was inaugurated by Karanveer's school principal Ms. Manju Balasubramanyam. The rock band entertained the group with a rendition of Pink Floyd's "We don't need no education!"

DART also celebrated its achievement in winning PTC Therapeutics' 2016 STRIVE award by cutting another cake with icing to match the award certificate! After this began the free flow of more fun and games and eats with a *chaat* corner serving up delicious *pani puri* and *papdi chaat* all made by parents of children. The children also enjoyed a round of light games and even won prizes.

The event was rounded off with distribution of a year's worth of medicine to underprivileged children.

For all those who attended the event, the day was a wonderful memory of joy, happiness and adding to the health and wellbeing of children with muscular dystrophy.

What is Duchenne Muscular Dystrophy?

Duchenne muscular dystrophy (DMD) is one of the nine types of muscular dystrophy. This inherited genetic disorder leads to progressive muscular degeneration and weakness. The gene that produces the protein dystrophin is faulty thereby causing a near absence in production of this vital protein required for muscle tone and strength. This disorder mainly affects boys and appears in early childhood. It is usually noticed when the child finds it difficult to attain normal developmental milestones like standing and walking with ease. DMD is an x-linked disorder thereby transmitted from mother to son.

Boys with DMD usually need to use a wheelchair by the age 12-14 years. DMD slowly affects respiratory and cardiac muscles and some boys may need additional oxygen therapies for steady breathing. Currently there is no cure except physiotherapy, rehabilitation and steroid treatment. However, there are many curatives on the anvil like gene therapy and exon skipping.

References:

1. What is Duchenne muscular dystrophy? - (https:www.mda.org/disease/duchenne-muscular-dystrophy)
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3. What is Duchenne? - (http://www.cureduchenne.org/about-duchenne.html)

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