

Dromore Leader

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Charity lays out £175,000 in funding SAM to benefit from drugs research

IN a landmark move, local charity SAM (Struggle Against Muscular dystrophy) has announced the award this year of more than £175,000 to evaluate three promising drugs targeting Congenital Muscular Dystrophy.

CMD is the little-known form of the disease that afflicts the charity's inspiration, three year-old Hillsborough boy Sam McCausland.

Sam's mum, and charity founder, Tracy McCausland claims that while there are currently no effective treatments or cures for any of the more than 40 neuro-muscular conditions in the Muscular Dystrophy group, research has so far largely bypassed Sam's rare form.

"As a rare disease," she said, "the form of muscular dystrophy from which Sam suffers (merosin deficient congenital muscular dystrophy, MDC1A for short) has until now been largely ignored in research and drug development.

As well as funding research into an NFKappaB inhibitor, laminin 111, and a muscle-specific IgF upregulator, SAM is also to fund a separate effort, in association with international CMD advocacy group, CureCMD - to identify disease biomarkers specific to merosin deficient CMD (MDC1A).

It has been two years since Tracy and her husband William had news that their little boy Sam - just one year old at the time - had the progressive muscle wasting condition that is Congenital Muscular Dystrophy.

Muscular Dystrophy affects thousands of UK children, causing the muscles to gradually waste away. Children become dependent on wheelchairs at a very early age and as the muscles continue to waste they become quadriplegic, suffer from scoliosis (twisting and distortion of the spine) and develop painful muscle contractures.

They also lose the ability to breathe and eat without assistance.

Said Tracy, "In April 2008 we set up the



Sam McCausland, the inspiration behind the Struggle Against Muscular dystrophy charity.

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charity 'Struggle Against Muscular dystrophy': just over one year on, with huge support both financially and emotionally from the people of Northern Ireland and a number of extremely successful fundraising events under our belts, we have raised almost £200,000.

"One of our core commitments was that we would establish and run as a 'zero cost' charity; in other words everyone involved with the charity would give freely of their

time, expertise, products and services so that we could be in a position to promise faithfully that every pound we raise can go to research to help bring an effective treatment and eventually a cure one step closer."

With the recent funding announcement, SAM, she said, was being true to its word. She added, "Each application received during this year's grant process was subjected to a rigorous review process that included outside peer review and Scientific and Medical Advisory Board evaluation."