

myotubular trust

FINDING STRENGTH



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<small>Data Protection Act 1998. The data collected in this form may be used for the purposes of sending you more information about the Myotubular Trust. The data will not be disclosed to any organization that is not associated with the Myotubular Trust. Please tick the box indicated on this sponsorship form if you wish to hear from us again.</small>					Amount Carried Forward:	

Thank you for your generosity!

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What is the charity, Myotubular Trust?

There are three genetically distinct forms of Myotubular Myopathy.

The commonest is x-linked, affecting only boys, and also the most severe. It usually presents in the newborn period and there is associated breathing and swallowing difficulties in addition to the general muscle weakness. The other forms are either dominant or recessive in inheritance, are usually milder and vary widely.

Our logo represents the muscle cell of someone with Myotubular Myopathy. In normal muscle development the central nucleus will go to the outside edge of the cell and use a protein called “myotubularin” to become strong and healthy. In the baby with Myotubular Myopathy the “myotubularin” protein is missing which means that the muscles remain in the very weak stage of development. So as well as causing general muscle weakness, many sufferers need mechanical ventilation to stay alive and need to be fed straight into the stomach via a gastrostomy. Many are medically very fragile and need nursing care 24/7 for at least the first few years of life. Sadly, many babies are too weak and die from complications associated with the condition.

The exciting news is that there are recent and major breakthroughs in the world of muscle disease and, for us, that means there is real hope of a cure. The problem remains finding enough funds to translate these broader discoveries into results for the rare conditions, like myotubular myopathy. When we investigated what needed to be done to keep pace with the scientific possibilities, we realized that a specific research fund was our only option to help extend the lives of these children.

Therefore, the Myotubular Trust was created in February 2006. Our goal is to help fund research to find a treatment or cure for myotubular myopathy, giving children a real chance of living.

We are very fortunate to have the full and enthusiastic backing of the most eminent researchers in the field. *“Money is absolutely required to fund research...and this is where charities like the Myotubular Trust have great value....It takes enthusiastic people to bring things ahead of schedule”* Professor F Muntoni, Professor of Pediatric Neurology, Head of Dubowitz Neuromuscular Centre, Institute of Child Health, Great Ormond Street Hospital for Children, and Scientific Advisor to Myotubular Trust.

We are so grateful to you for taking on the extraordinary job of helping us to raise desperately needed funds. One day these children will survive, and that is due to wonderful people like you! Thank you for your generosity.

email: contact@myotubulartrust.org

www.myotubulartrust.org

Registered Charity No: 1113809

Founding Patron: Professor V Dubowitz, Emeritus Professor of Paediatrics, Imperial College, London. President of World Muscle Society.
Scientific Advisor: Professor F Muntoni, Professor of Pediatric Neurology and Head of Dubowitz Neuromuscular Centre, Institute of Child Health, Great Ormond Street Hospital for Children, London.