



Myotubular Myopathy is a rare and devastating muscle weakness, affecting mainly boys, from birth. More particularly it severely affects the muscles used to swallow and breathe. These babies and children are at a constant risk of dying, and usually from complications due to simple colds and coughs from which they are literally too weak to recover. Most do not survive their babyhood or early childhood, and very sadly only 1% makes it to 10 years old.

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 rarer conditions, like myotubular myopathy. When we investigated what needed to be done to keep pace with the scientific possibilities, we realised that a specific research fund was our only option to help extend the lives of affected 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 Francesco Muntoni, Myotubular Trust scientific advisor.

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 kindness and generosity!

If you can further help our charity, please email Wendy, Anne or Mel at: contact@myotubulartrust.org

Registered charity: 1113809. Founding Patron: Professor Victor Dubowitz, Emeritus Professor of Paediatrics, University of London, President of World Muscle Society. Scientific Advisor: Professor Francesco Muntoni, Professor of Paediatric Neurology, Institute of Child Health based at Great Ormond Street Hospital for Children.

www.myotubulartrust.org

myotubular trust

FINDING STRENGTH



STANDING ORDER FORM

To:	Bank	Sort Code:
		Account No:
Postcode:		
Please pay to CAF Bank Ltd, Sort Code: 40-52-40 Account No: 00014444 Myotubular Trust, the sum of:		£ (in words) £ (in figures)
Commencing	day of / (month)	/ (year) 200
and the same amount annually on*	day of / (month)	
OR the same amount monthly on*	day of each month	
The final payment being on	day of / (month)	/ (year) 200 /or until further notice*
Signed:	Dated:	

*delete as appropriate

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Myotubular Trust can reclaim the tax back on your donation and get an extra 28% without it costing you a single penny. Please tick the gift aid box if you are a tax payer and would like us to Gift Aid your donation and make sure we can read your full name, home address and postcode. This supports our tax claim and will not be used to contact you. Please note that you must have paid an amount of income tax, and/or capital gains tax at least equal to the amount we will claim in the tax year you make the donation to us. Unfortunately, we cannot reclaim tax back on company donations, only individuals.

Please claim Gift Aid on all donations I have made to the Myotubular Trust since 6 April 2005 and all donations I make in the future until I notify you otherwise.

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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 if you do not wish to hear from us again.

Please send the whole form to:

Myotubular Trust
c/o Chalkdell Management Accountants Ltd
15a Barnard Road,
London
SW11 1QT

email: contact@myotubulartrust.org www.myotubulartrust.org

Thank you for your generosity!

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Thank You



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