

...when?

We need help now! If you can help our charity by providing cash, time, fundraising or simply good ideas, please contact:

Wendy Hughes, Trustee on: **07813 200298**

Anne Lennox, Trustee on: **07885 309753**

Or email us at: **contact@myotubulartrust.com**



Donate online securely using your credit or debit card (£, US\$ or Euros) at www.myotubulartrust.com



Make payments by UK cheque payable to "Myotubular Trust" and post to:
James Rosling, Trustee, Myotubular Trust, c/o Chalkdell Management Accountants, 15a Barnard Road, London, SW11 1QT.



Set up a regular standing order from your bank account. Download a standing order form from our website or email us on: contact@myotubulartrust.com

Myotubular Trust : Registered Charity No 1113809

Myotubular Trust is run on an entirely voluntary basis with administration costs kept to an absolute minimum

myotubular trust
FINDING STRENGTH



...what?

What is Myotubular Myopathy?

There are three genetically distinct forms of Myotubular Myopathy. The commonest is the 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.

What is Myotubular Trust?

Like all rare diseases, it is very difficult to attract research funding for myotubular myopathy, despite the severity of its impact on the children and adults affected. The Myotubular Trust has been set up therefore to raise those funds and begin the process of finding a cure or treatment for Myotubular Myopathy.

The Myotubular Trust will benefit from scientific advice from Pediatric Neurologists with expertise in this condition, including Professor V Dubowitz, Emeritus Professor of Paediatrics and Professor F Muntoni, Professor of Pediatric Neurology at Imperial College, London at one of the largest Paediatric Neuromuscular Units in Europe which has been designated by the Dept of Health as the National Reference Centre in the UK for a series of congenital neuromuscular disorders.

What do we want to achieve?

We are setting up a fund, initially with a target of £200,000, to which interested European academics can apply for research projects that could potentially lead to a treatment or cure for myotubular myopathy. We will in the medium term be setting up the medical peer review process to manage these projects.

www.myotubulartrust.com

...why?

Myotubular Myopathy is a condition for which there is quite likely to be a cure, but finding the cure for rare diseases can be delayed by years, even decades from lack of funding. It just can't compete with cancer, diabetes, heart disease, etc for hard cash.

We are fortunate to have the full and enthusiastic backing of eminent academics in the European paediatric neuromuscular field who are clear in their views that a difference can be made with more research.

In a recent interview, our scientific advisor, Professor F Muntoni said:

“There is a lot of excitement regarding the role that muscle stem cell could play in the future in a number of neuromuscular disorders. In myotubular myopathy it is also likely that drug therapies could play a role in the not too distant future. But money is absolutely required to fund research. This is where charities like the Myotubular Trust have great value. It is useful for rare disorders to be recognised by having a specific charity. This can help families – and doctors – to make contact with each other and to swap information. It also helps to increase the profile of the condition and raise funds for important research. The money makes a huge difference.”



“If I had stronger muscles I would chase my sister without having to ask someone to pick me up”

Tom, age 3 who has Myotubular Myopathy still can't walk or even crawl and probably the toughest thing for Tom is that during every single day just breathing is difficult.

“I would love to walk”

Joshua, age 6 is unable to walk or even bear his weight. He is 24 hour ventilated with breathing support which he initiates by himself. Despite his problems he is a bright and happy 6 year old.



...how?

Please help us with fundraising. We have given some successful ideas on our website, but here are just a few examples of how you can help us:

- Recycle old print cartridges and phones – to join the scheme and find out where to send old cartridges or phones, see our [“easy fundraising”](#) ideas on our website.
- Shop online with many leading online retailers such as Amazon, M&S, Early Learning Centre, John Lewis, Virgin Wines and earn us commission. See our website [“easy fundraising”](#) for details.
- Organise your own event or get yourselves sponsored. See our [“Fundraising Stories”](#) page on our website for details. Easy events include [“chilli and wine”](#) nights where friends pay for your hospitality.
- Join our organised London 10K run in July 2007. We have 30 free spaces to give away on a first-come-first-served basis. Or take part in any sponsored event for us – many organised events allow you to raise funds for the charity of your choice.
- Ask your company to sponsor us as their [“charity of the year”](#) or organise fundraising events at work. See our [“corporate fundraising”](#) page on our website for inspirational ideas.
- Ask your company to join the [“pennies from heaven”](#) scheme where employees donate their loose change at the end of each month. Ask your company to nominate our charity. See our website [“corporate fundraising”](#) page for more details.

If you can't spare cash, but can spare time, we would be very grateful for your help. Please contact us - details on the back of this leaflet.

Thank you for your time and generosity!