

UK Registered Charity 1137177
A Company Limited By Guarantee

myotubular trust

Annual Report and Financial Statements

To the year ended
31 December 2025





TRUSTEES' ANNUAL REPORT 31 December 2025

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The Trustees of the Myotubular Trust take pleasure in presenting their annual report and the financial statements for the year ended 31 December 2025.

Objects and Activities
The objects of the Myotubular Trust as agreed by the Charity Commission are;

- the relief of disability and the extension of life for babies, children and adults suffering from myotubular myopathy
- by promoting the study of, and research into, the treatment and cure of the muscle weakness caused by myotubular myopathy.

We bring about the public benefit required of all charities, by the activities of:

- making grants to organisations and individuals
- providing support, advice, and information
- sponsoring research.

The Myotubular Trust's primary objective is to facilitate and fund medical research that advances treatments and, ultimately, help to find a cure for myotubular and centronuclear myopathy. Alongside this, the Trust provides support and information to families affected by the condition and works to enhance awareness among healthcare professionals, industry and the public.

To achieve these aims, the Trust raises funds through a combination of individual donations, corporate partnerships, grants from other Trusts and Foundations, and community-led fundraising initiatives. All activities are designed to ensure the best possible use of available resources, maximising impact for the community we serve.

Myotubular Myopathy and Centronuclear Myopathy
Myotubular myopathy is a rare and extremely life-threatening muscle condition, which causes profound muscle weakness, usually from birth. It is one of a group of conditions called ***centro****nuclear* myopathies – under a microscope the nucleus of the muscle cell of someone affected is in the ***centre***, rather than at the usual edge of the cell.

These conditions are genetic in inheritance. The gene mutation for x-linked myotubular myopathy is carried on the x chromosome (xlmtm), and is the most common form, affecting mainly boys. They usually do not survive their babyhood – the statistics have been under review in the last few years and the current view is that 50-75% die in their first year, and very few make it to adulthood. Even rarer genetic forms, either dominant or recessive in inheritance, can affect both males and females and are generally milder in severity, but not always. They usually emerge in adulthood, but again it is possible for children to be affected by these other forms. The terms myotubular and centronuclear myopathy both describe 'our' condition.
Children and adults with myotubular myopathy usually require vigilant nursing care, ventilators to breathe, power wheelchairs to get around, and are often fed via a tube into the stomach.

Females who have a confirmed alteration on the MTM1 gene were often referred to as 'carriers' of the condition, meaning **they can pass on the altered gene**. They often do not experience symptoms, but sometimes, a female carrier may have symptoms of XLMTM, such as, but not limited to, muscle weakness, fatigue, muscle pain and muscle cramps. These symptoms are often mild but can be severe in rare cases. There is a growing view that affected women should not be referred to merely as 'carriers' as this may underplay any symptoms they are experiencing. It is now thought that women who are experiencing symptoms, even if mild, should be referred to as ***'women with XLMTM'.***

Women with symptoms, and those affected by some of the rarer forms which can manifest in adult life, may develop muscle weakness and problems with eating and drinking; walking and movement; muscle fatigue and susceptibility to respiratory weakness and associated infections. It can even be fatal for a small number of seriously affected women.

While myotubular myopathy has historically been considered primarily a muscle disease, and care has focused on the respiratory challenges and complications, the last five years have shone a light on liver complications too. In all three of the clinical trials for myotubular myopathy (XLMTM) and centronuclear myopathy (CNM), adverse events were reported in liver function tests, and all three were prematurely halted for this reason. Tragically, four boys died in the gene therapy trial. A new push in our field is underway in order to understand how the liver is impacted and what that means for future clinical trials and, just as importantly, for day-to-day care of all patients.

2025 – where are we now

In the 19 years since the Myotubular Trust was founded, the landscape has changed markedly. Day-to-day management of the condition has improved with evolving respiratory support techniques and, wonderfully, many children are living longer. The change in survival data is truly something to be celebrated. Substantial progress has been made in understanding myotubular and centronuclear myopathy in those 19 years, and research into a treatment, or cure, has made great steps forward, including the first human clinical trials.

However, there remain many fundamental questions about the condition, and why and how these genetic variations, and the proteins they impact, cause muscle weakness. There have been heartbreaking setbacks in the clinical trials due to serious liver adverse events. Combined with the history, outside of clinical trials, of some of those with XLMTM (but not all) suffering from liver complications over the years, the community now urgently needs to uncover the true natural history of the liver, and the mechanism of action by which a lack of myotubularin is implicated in the liver.

The Trust was established in 2006 by two parents of boys with myotubular myopathy, simply to raise research funds. There was such hope when, only 10 years later, the first human clinical trials began for myotubular and centronuclear myopathy, and the difficult years that have ensued since then have shown us how important it continues to be to keep these conditions at the forefront of groundbreaking research.

We are dedicated to continuing to make a meaningful difference - there is clearly a vital role for a disease specific research funder in the world of rare disease, along with a tangible need to support patients and families. We are conscious though of 'Founder syndrome' and the voice of the living patient. We aim to take every opportunity to invite in other patients, parents and families to take key roles and become leading voices in this work.

Since founding in 2006…we have:

1. Raised over ***£3M,*** through family-led fundraising, networks and relationships.
2. Made ***19 research grants*** to researchers in world class laboratories, with the support of a highly regarded Scientific Advisory Board.
3. Funded the proof of principle project for gene therapy that led to the ***first ever clinical trial*** for myotubular myopathy.
4. Funded ***other proof of principle projects*** that progressed to the only other two human clinical trials for our condition.
5. Funded research grants that contributed to the discovery of ***two new genes*** implicated in centronuclear and myotubular myopathy.

6. Hosted ***five family conferences***, bringing together affected individuals and families, researchers, clinicians, and other health professionals, and arranged several family meetings by ***Zoom both during the pandemic and beyond*** with presentations from, and discussions with, global experts and scientists.
7. Created the first disease specific international ***Patient Registry*** to gather vital information on the condition and funded its migration to the stability and credibility of a university setting.
8. Participated in a European Neuromuscular Centre workshop on Mouthpiece Ventilation, resulting in the publication of ***MPV international best practice guidelines***.
9. Been invited on an ongoing basis by ***Great Ormond Street Hospital Children's Charity*** to be one of their small number of rare disease charity partners in their annual national funding call focusing on complex or rare childhood diseases.
10. Sponsored a ***Standards of Care*** meeting for clinicians, patients, and their healthcare professionals at the Royal Brompton Hospital.
11. Presented for LifeArc on ***drug repurposing for rare diseases*** and contributed to their published expert advice.
12. Contributed to the first ever ***Congenital Myopathies Masterclass*** for European healthcare providers. The Masterclass was organised by TREAT-NMD and included sessions led by world leading experts on myotubular and centronuclear myopathy.
13. Sponsored the UK focus group that contributed to the international study, and subsequent journal publication, ***Lessons Learnt from Clinical Studies in Centronuclear Myopathies***.
14. Created a great band of ***committed supporters***, raising funds for us year on year.
15. Developed strategic relationships with ***key stakeholders*** in the fields of neuromuscular disease, rare disease, and UK regulatory bodies.
16. We co-fund research projects with highly regarded UK charities - Great Ormond Street Hospital's Charity, and the UK umbrella muscle disease charity, MDUK.
17. And *most importantly,* brought together ***families*** affected by myotubular and centronuclear myopathy, who support the Trust's fundraising and each other's lives.

In 2025 specifically we have:

1. Raised £146,956.
2. Continued to substantially add to our Family Factsheets, the purpose of which is to share personal family case studies to support other families in their care and decision making.
3. Brought together the recipients of the Trust's three liver-focused research grants for a scientific meeting in London, creating an opportunity to share work in progress, benefit from peer review and strengthen collaboration across projects addressing one of the most urgent challenges facing the myotubular myopathy community.
4. Continued our collaboration with the US patient organisation, MTM-CNM Family Connection, to run the MTM-CNM Liver Collaborative Working Group, bringing together a range of leading global experts, scientists, experienced clinicians, and biotechs, to fast-track cooperation on the understanding of liver issues emerging from current clinical trials.
5. Worked with the Myotubular and Centronuclear Myopathy Patient Registry, through the Liver Collaborative, to continue to communicate the value of new sections of academic, clinical and patient curated questions about both liver health and nutrition, and supported the Registry in the development of a poster for World Muscle Society on genetically confirmed XLMTM females.
6. Participated in Genomics England's podcast for Rare Disease Day 2025 to explore the challenges and opportunities shaping the future of rare condition therapies.
7. Continued to project manage a research team to investigate possible muscle symptoms and lived experience of women with XLMTM in the UK and Ireland.

Every single year since founding in 2006, we have raised 100% of our running costs separately from the funds raised by families and supporters, meaning that once again in 2025 we met our ambition to channel all the funds raised by supporters into research.

Family Support in 2025

Advocacy and Family Support
Specific support is needed for myotubular and centronuclear myopathy patients and families, mainly because of the rarity of centronuclear and myotubular myopathy. Usually, the child's or patient's GP or doctor will never have come across the condition before - making being diagnosed a frightening and bewildering experience for all concerned. Being hurled suddenly into a world of medical jargon; high level nursing; and complex healthcare and social care systems, families and individuals are grateful to know they are not alone, and that we, and others like them, are willing to share the burden of responsibility by helping them understand their experiences and how to navigate the systems.

At a time when parents are supposed to be celebrating the birth of an infant, our families are often instead in the position of having to make important choices around giving their child the best quality of life, and a chance of longer-term survival. The information these families are given by their hospital care teams to make those decisions can be patchy and possibly delivered by someone who has never seen a child with the condition before. When a baby is finally stable enough to go home, it is not unusual for the transition process from hospital to home to take 1 year to 18 months.

The need for support/information caused by a lack of understanding of the impacts of such a rare, devastatingly life threatening condition re-emerges many times throughout a patient's life – and particularly at times of change, such as when there is a physical change (such as losing the ability to walk or developing scoliosis), during periods of ill health, when moving home or into a new phase of education or work, around family planning, or practical day-to-day living issues.

In 2025 we have supported families who were:

- Moving to palliative care from a neonatal setting
- Establishing a care plan for a move to home
- Seeking advice on the most appropriate seating equipment for their child
  Enquiring about the current status of clinical trials and future potential research
- Supporting changes in nutrition plans while hospitalised
- As an adult affected by CNM, applying for early retirement due to physical deterioration
- Receiving a diagnosis of Parkinson's and attempting to establish the link with myotubular myopathy

In 2025, while providing support for individual issues for families, we also continued to add to ***Factsheets***, our substantial repository of publicly available patient case studies and experiences that are shared in order to help improve the standards of care and quality of life of our community. We are very grateful to all the patients and families who have contributed to these case studies. They are invaluable.

The global closed Facebook group managed by Myotubular Trust – ***Myotubular Myopathy*** - continues to go from strength to strength, with membership reaching over 1,000 members by the end of 2025. This group continues to provide real-time, real-life advice and perspectives for families who regularly tell us they'd be very alone without this community.

Research in 2025

The Myotubular Trust was set up to raise funds to leverage research findings being made, and techniques being trialed, in 'more common' muscle diseases. The ultimate goal of the Trust is to invest in a diverse number of routes to a cure for all genetic forms of myotubular and centronuclear myopathy, or in treatments that alleviate the most severe symptoms. We do this by investing in the very best translational research, peer reviewed to the highest international standards, supported by an eminent Scientific Advisory Board.

The Myotubular Trust was very gratified to have provided proof of principle funding for all three of the clinical trials that came to clinic in the last 10 years. We sincerely thank those affected by myotubular and centronuclear myopathy who took part in these. Clinical trials, particularly for conditions as severe as ours, require enormous commitment in terms of time, travel, logistics and patience. We thank them for adding to the sum knowledge of our understanding of the condition.

Current grants

It is very clear that for research into a treatment for myotubular and centronuclear myopathy to progress, we need to understand more about how the liver is affected, and what goes on when there are liver complications.

Next generation gene therapy

Dr Ana Buj Bello was the recipient of the first ever research grant from the Myotubular Trust in 2008 for her pioneering work on gene replacement therapy for xlmtm. The goal of our current grant to Dr Buj Bello and her team at Genethon is to develop an even more specific and potentially safer 'vector' to carry the missing protein, myotubularin, to muscle cells. An approach which they hope will ultimately be brought to clinical trial. They also aim to better characterise the liver in laboratory tests, both before and after gene therapy. Based on this understanding and new developments in the technology of AAV vectors, they aim to generate optimised vectors with increased potency and specificity for MTM1 gene delivery.

Studying liver disease in X-linked myotubular myopathy

Dr Jim Dowling has been the recipient of a number of research grants from the Myotubular Trust. The purpose of our current grant to Dr Dowling and his team at Sick Kids is to better understand the cause of liver disease in people living with XLMTM, and to help develop a treatment. This grant was made in partnership with the UK muscle disease charity, MDUK. We are delighted to be partnering with MDUK on this important grant, and believe it is testament to how vital it will be for myotubular myopathy, and likely many other neuromuscular conditions, to better understand the impact of gene therapy, and other treatments, on the liver in clinical trials.

An Advanced Multi-Organoid Platform for Therapy Modelling in X-Linked Myotubular Myopathy

In 2024, as part of their annual grant call for rare paediatric disease, we partnered with Great Ormond Street Hospital Children's Charity in a three-year grant of £248,940 to Professor Francesco Saverio Tedesco and Dr. Valentina Maria Lionello at University College London. This project focuses on creating patient-specific 3D 'mini-muscles and livers' using human induced pluripotent stem cells reprogrammed from individuals with X-linked myotubular myopathy (XLMTM). These models aim to enhance our understanding of the disease and serve as platforms for testing potential gene therapies.

These liver focused grants underscore our commitment to funding and facilitating research that enhances understanding and that paves the way for effective treatments for myotubular and centronuclear myopathy.

We are immensely grateful to our Scientific Advisory Board (SAB) for their time and their expertise and understanding to bring excellence and rigor to our funding decisions. The calibre of applications the Myotubular Trust attracts is due, in no small part, to the reputation of this group of scientists.

The academic members of the SAB are:

- Professor Francesco Muntoni, Head of the Dubowitz Neuromuscular Centre, Great Ormond Street Hospital
- Dr Meriel McEntagart, Consultant Clinical Geneticist, St. George's Hospital, London
- Professor Michael Duchen, Professor of Physiology, University College London
- Dr Susan C Brown, previously Reader in Translational Medicine, Department of Veterinary Basic Science, Royal Veterinary College, University of London
- Professor Volker Straub, Harold Macmillan Professor of Medicine, Consultant in Neuromuscular Genetics and Paediatrics, Newcastle University
- Professor Dominic Wells, previously Professor in Translational Medicine, Royal Veterinary College

We are indebted for the guidance they gave to the Myotubular Trust throughout the year. We are also very grateful to the lay members of our SAB for their time. The lay members include parents, bereaved parents and patients.

Financial Review

Achievements and Performance in 2025

2025 was another year of steady progress for the Trust. Through the generosity of grant makers, individual donors, family-led fundraising and corporate supporters, we were able to continue investing in research, supporting families and strengthening our collaborative work across the neuromuscular community.

We were particularly grateful for grants from IGY Foundation, BBC Children in Need, Hospital Saturday Fund and Astellas Pharmaceuticals. We also continued our valued research partnership with MDUK on projects of shared scientific importance for neuromuscular disease.

Together, these grants and partnerships enabled us to sustain our commitment that funds raised by families and their friends and supporters are directed towards research, while separately funded running costs supported the day-to-day operation of the charity.

We also received income from both Astellas Pharmaceuticals and the contract research organisation PPD in recognition of work undertaken by the Myotubular Trust, reflecting the value of the Trust's expertise and contribution to the wider neuromuscular and rare disease community.

Community and Fundraising Activities

Our dedicated community of supporters once again played an essential role in raising both awareness and funds during 2025. Trust-led events included the London Hope Walk attended by supporters from across the UK and overseas, even including a family who travelled from Australia to take part, and the launch of our first ever Liverpool Hope Walk. We were also grateful to those supporters who secured matched funding from employers for their Hope Walk sponsorship, significantly increasing the impact of their fundraising efforts.

During the year we were delighted to secure sponsorship for a new range of Trust t-shirts, helping to raise awareness of myotubular and centronuclear myopathy while supporting our fundraising activities.

Beyond Trust-led activities, families, their friends, colleagues and supporters demonstrated extraordinary generosity through a wide range of fundraising initiatives. These included the 19th Jack Blunsdon Golf Day, Yorkshire Tough Mudder, fundraising runs undertaken by Patrick, and a bike ride and run in Northern Ireland.

We were especially touched by the many donations made to celebrate milestones and remember loved ones. These included donations given in lieu of gifts at a 40th wedding anniversary celebration, gifts marking special family anniversaries, and donations made in memory of memory of family members, grandparents and great-grandparents.

Supporters continued to raise funds through Easyfundraising, turning everyday online shopping into donations for the Trust at no additional cost to themselves. We also received many generous Christmas donations, providing a welcome boost to our year-end fundraising efforts.

We remain immensely grateful for the loyalty of our regular supporters who give through Direct Debit and Give as You Earn schemes. These regular donations provide an important and dependable source of income, enabling us to plan our activities with greater confidence.

Employer-supported giving continued to make a valuable contribution to our income thorugh matched funding schemes, donations linked to employee volunteering hours and charitable nomination programmes. We are very grateful to the organisations and employees who chose to support the Trust in these ways.

What continues to humble us is the deeply personal nature of so much of our fundraising. Whether through a sporting challenge, a family celebration, a tribute to a loved one or a regular monthly gift, every contribution reflects a desire to improve the future for people affected by myotubular and centronuclear myopathy. To every supporter who played a part in 2025, we offer our heartfelt thanks.

Fundraising Practice

The Trustees take their responsibilities to fundraising very seriously. To that end, we ensure that we adhere to the Fundraising Regulator's code of best practice and meet the Charity Commission's six principles of charity fundraising. For us, at our size, the areas of best practice we pay attention to are;

- providing information on how to fundraise safely,
- considered communication with all fundraisers, which is appropriate to our strategy,
- carrying out a proportionate process of due diligence around fund raising proposals,
- making a record of the issue and return of any charity collection materials,
- securing cash donations and banking them as soon as possible,
- not sharing personal data without explicit consent,
- including opt-out information on fundraising communications sent to a named individual,
- processing unsubscribe requests in a timely way,
- using funds as they have been directed by specific donors, in particular allocating restricted funds appropriately.

We adhere to the Data Protection Act 2018, General Data Protection Regulation (GDPR) and pay data protection fees to the Information Commissioner's Office (ICO).

Reserves Policy
The Trustees sole aim in expending cash reserves is to fund research into a cure or treatment for myotubular myopathy and they do not consider it appropriate to hold long-term reserves.

However, as each research project is granted, those funds will be held available to be released in staged payments, and new awards will only be made if the full cost of the relevant research project is available, and available to be ringfenced. This prudent financial policy is appropriate given our size and specialism.

Plans for future periods

The Trust aims in 2026 to:

- Maintain excellence in family support, advocacy, information provision – in particular our Factsheets focus - and continue to make the introductions that families tell us are invaluable.

- Organise and support Hope Walks in London, Liverpool and in at least one other location in the UK or Ireland.

- Promote, and fund research that furthers our understanding of the liver and bile function in myotubular myopathy, with the goal of being able to impact both clinical trial planning and ongoing patient care.

- Continue to support the development of a UK carrier women study, building on the excellent work already being done in the Netherlands and Germany.

- Organise webinars on key topics of interest for the patient community and investigate the interest in meeting in person once again.

- Continue to work with key stakeholders in the neuromuscular disease community, and strategic rare disease organisations.

- Continue to work with regulatory authorities on behalf of patients with myotubular and centronuclear myopathy.

- Continue to share information with, and promote collaboration between, other family and patient organisations, relevant scientific interest groups and research organisations.

- Continue to secure separate funding for running costs to uphold our pledge of investing 100% of funds raised by families and their networks directly to research.

Reference and administrative details of the Charity, its Trustees and advisors
The following were Trustees of the Trust and held office during the above period:
Patricia Allen
Lisa Basholm
Zak Hughes
Andrew Lennox
Anne Lennox
James Rosling

Following many years of valued service, Gary Browning retired as a Trustee during 2025. The Board wishes to place on record its gratitude for his dedication to the Trust over many years, and for the important role he has played in supporting our work and mission.

We are delighted to have welcomed two new Trustees during the year, Lisa Basholm and Zak Hughes. Their appointment strengthens the range of experience and expertise available to the Board, and we warmly welcome them to the Trust.

Trustees are appointed by the board of trustees and serve for three years (five years for Anne Lennox) after which period they may put themselves forward for re-appointment. The trustees meet three times per annum.

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Myotubular Trust
- charity registration number 1137177
- company registration number 07260229

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Independent Examiner
Michael Stone MA ACA
Jamieson Stone LLP
Windsor House
40/41 Great Castle Street
London W1W 8LU

Structure, Governance and Management

Constitution
The Myotubular Trust is an incorporated charity limited by guarantee and its governing document is the memorandum and articles of association dated 21 May 2010. The memorandum and articles of association has the same objects as that of the Trust Deed dated 26 January 2006 of the unincorporated charity. The Trust obtained charitable status under Section 4 of the Charities Act 1960 from the Charity Commission on 19 April 2006 under registration number 1113809 and following incorporation on the 20th May 2010 was registered with the Charity Commission with registration number 1137177, and with Companies House with company registration number 7260229.

Organisation and the Trustees
In selecting individuals for appointment, the trustees will have regard to the skills, knowledge and experience needed for the effective administration of the charity.

Trustees' responsibilities statement

The Trustees (who are also directors of The Myotubular Trust for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards.

Company law in England and Wales requires the Trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). The financial statements are required by law to give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing these financial statements the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles of the Charities SORP
- Make judgments and estimates that are reasonable and prudent
- State whether applicable UK accounting standards have been followed and statements of recommended practice, subject to any departures disclosed and explained in the financial statements and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue to operate.

The trustees are responsible for keeping accounting records, which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Risk management
The trustees have examined the strategic, business and operational risks, which the charity faces and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to lessen the risks.

INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 31 DECEMBER 2025

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purpose of company law) are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

Having been satisfied that the charity is not subject to audit under company law and is eligible for independent examination it is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and the seeking of explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently, no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

1) which gives me reasonable cause to believe that in, any material respect, the requirements:
   - to keep accounting records in accordance with section 130 of the Charities Act; and
   - to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the Companies Act 2006 and with the methods and principles of the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) have not been met; or
2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Michael Stone MA ACA
Jamieson Stone LLP
Windsor House
40/41 Great Castle Street
London
W1W 8LU

17/9/2026

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2025

	Unrestricted Funds £	Designated Funds £	Restricted Funds £	Total Funds 2025 £	Total Funds 2024 £
INCOMING RESOURCES					
Donations and grants	64,065	51,000	-	115,065	105,730
Fundraising activities	26,245	-	-	26,245	27,533
Interest received	5,646	-	-	5,646	5,153
Total incoming resources	95,956	51,000	-	146,956	138,416
RESOURCES EXPENDED					
Research	-	248,836	-	248,836	89,453
Liver meeting conference	-	4,923	-	4,923	-
Fundraising costs	4,959	-	-	4,959	2,438
Staff costs	49,961	-	-	49,961	49,961
Training	313	-	-	313	103
Accountancy & payroll	598	-	-	598	366
Independent examiner	1,000	-	-	1,000	1,000
Legal & professional	67	-	-	67	92
Trustee's indemnity	1,090	-	-	1,090	1,042
Travel costs	150	-	-	150	954
Postage & telephone	267	-	-	267	105
Subscriptions	85	-	-	85	205
Web & IT costs	2,130	-	-	2,130	2.380
Bank charges	291	-	-	291	210
Miscellaneous costs	-	-	-	-	-
Total resources expended	60,911	253,759	-	314,670	148,309
Net incoming/(outgoing) resources	35,045	(202,759)	-	(167,714)	(9,893)
Transfers between funds	(35,045)	35,045	-	-	-
Net movement in funds	-	(167,714)	-	(167,714)	(9,893)
Total funds brought forward	8,216	405,187	-	413,403	423,296
Total funds carried forward	8,216	237,473	-	245,689	413,403

All gains and losses arising in the year are included within the statement of financial activities

The accompanying notes form part of these financial statements

BALANCE SHEET
AS AT 31 DECEMBER 2025

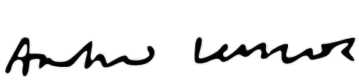
	£	2025 £	£	2024 £
CURRENT ASSETS				
Debtors and prepayments	6,208		2,241	
Cash at bank and in hand	241,564		413,382	
Total current assets	247,772		415,623	
CREDITORS				
Amounts falling due within one year	2,083		2,220	
Net current assets		245,689		413,403
NET ASSETS		245,689		413,403
FUNDS OF THE CHARITY				
Restricted funds		-		-
Unrestricted general funds		8,216		8,216
Unrestricted designated funds		237,473		405,187
		245,689		413,403

The company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2025 and the members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2025 in accordance with Section 476 of the Companies Act 2006.

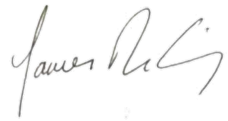
The directors acknowledge their responsibilities for: (a) ensuring that the company keeps accounting records which comply with Sections 386 and 387 of the Companies Act 2006 and (b) preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of each financial year and of its profit or loss for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

The financial statements have been prepared in accordance with the provisions of Part 15 of the Companies Act 2006 relating to small companies.

The financial statements were approved by the trustees on …… and signed on their behalf:



……
Andrew Lennox
Chairman/Trustee



……
James Rosling
Treasurer/Trustee

The accompanying notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

1. BASIS OF PREPARATION

The financial statements have been prepared on the accruals basis of historic cost in accordance with the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) and the Companies Act 2006 and the Charities Act 2011.

2. ACCOUNTING POLICIES

Incoming resources

Incoming resources are recognised when the charity becomes entitled to the resources, the trustees are virtually certain they will receive the resources, and the monetary value can be measured with sufficient reliability.

Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the Statement of Financial Activities.

Grants and donations are recognised when the charity has unconditional entitlement to the resources.

Incoming resources from tax reclaims are recognised at the same time as the gift to which they relate.

Contractual income and performance related grants are recognized once the related goods or services have been delivered.

Investment income is included in the accounts when receivable.

Resources expended

Resources expended are recognised as soon as there is legal or constructive obligation committing the charity to pay out resources.

Resources expended include attributable VAT which cannot be recovered.

Funds

Restricted funds are funds to be used for specific purposes as declared by the donor.

Designated funds are monies set aside from general funds and designated for specific research awards by the trustees.

Unrestricted funds are donations and all other incoming resources without a specified purpose and which are available as general funds.

3. TAXATION

The Myotubular Trust is a registered charity and is not liable to Income Tax or Corporation Tax on income derived from its charitable activities.

4. RESOURCES EXPENDED

	2025	2024
	£	£
Research	253,759	89,453
Independent examiner's remuneration	1,000	1,000

The principal research grants awarded during the year were as follows:

	2025	2024
	£	£
Sick Kids	163,964	36,036
Inserm(Buj Bello) 2023-25	54,605	32,682
Great Ormond Street (GOSH)	20,750	20,735
Radboud 2025	9,517	-

5. DEBTORS AND PREPAYMENTS

	2025	2024
	£	£
Gift Aid	610	1,241
Prepayments and accrued income	5,598	1,000
	6,208	2,241

6. CREDITORS FALLING DUE WITHIN ONE YEAR

	2025	2024
	£	£
Accruals	2,083	2,220

7. RELATED PARTY TRANSACTIONS

There were no related party transactions by the trustees for the year (2024: None).

One Trustee received remuneration of £20,000 during the year ending 31 December 2025 (2024: £20,000).

The trustee's remuneration and other administration costs are funded from unrestricted corporate and charitable donations, which were specifically raised for that purpose.