

Myositis UK

Registered Charity Number: 327791



**Trustees Report and Financial Statements
For the year ended 31st March 2025**

Myositis UK

Trustees Report 2025

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Myositis UK - Charity Registration Number 327791

Reference & Administrative Information

For the Year Ended 31st March 2025

Myositis UK

Charity Registration Number 327791
Date of registration 26 April 1988
Registered Office 146 Newtown Road
 Woolston, Southampton
 SO19 9HR

Trustees

Mr Les Oakley, MBE Chairman
Mrs Paula Jordan Honorary General Secretary
Mrs Joanne Goode Honorary Treasurer

Staff

Irene Oakley
Myositis UK Co-ordinator

Names and Address of Advisors:

Bankers: CAF Bank Limited Lloyds TSB
 Kings Hill, West Malling PO Box 112, Canons House
 Kent, ME19 4TA Canons Way, Bristol, BS9 97L

Independent Examiner: Bridget Kalloushi
 ACIE
 6, Linden Road
 Muswell Hill N10 3DH

Medical Advisory Panel

Chair – Professor Mike Hanna, University College London
Vice Chair – Neil McHugh, University of Bath
Liaison to the Board of Trustees – Professor Hector Chinoy, The University of Manchester
SAC Chair – Professor Lucy Wedderburn, Institute of Child Health (University College London)

Scientific Advisory Committee

Chair – Professor Lucy Wedderburn, Institute of Child Health (University College London)
Professor Pedro Machado, University College London
Dr Janine Lamb, University of Manchester
Dr Liza McCann, Alder Hey Hospital/University of Liverpool
Dr James Lilleker, The University of Manchester
Dr Patrick Gordon, King's College London
Dr Gita Ramdharry, University College London

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For the Year Ended 31st March 2025

Chairman's review

Progress is a word that can at times be overused when commenting about the events of a charity year. However, progress has been evidently made and it is a pleasure to briefly report on the successful work of the charity and all who are connected to it. It has amazed me at how much hard work has been undertaken by those actively involved with the charity in particular trustees, Jo Goode our honorary treasurer, Paula Jordan our secretary. Also, Bridget Kalloushi for auditing our accounts and Laura Northcote for maintaining our website. There are nearly six hundred members in the charity and this is a genuine figure because we ask members to renew on a regular basis. This has enabled the charity to keep running costs to a level where information is sent out to those who still wish to receive our information. The work carried out by the trustees, members and friends and other associated activities that have successfully taken place and are a pleasure to report on. As a charity we endeavour to firstly raise money for sound research and secondly provide information and advice.

The first event I have the pleasure of reporting on is the London Marathon on Sunday 21st April 2024. The runners of "Team Muscle" who took part raised over an amazing £27,000 for the charity. Many of the runners friends and family joined us in St James's Park to celebrate their achievement. The team deserve our utmost respect and credit for the effort and no doubt pain they have made to help us. Simply, an inspirational team of runners.

The Myositis UK grant process for funding is working well with the invaluable support of Paul New at Manchester and the collective input from members of our medical and scientific committees. The Trustees have awarded five grants totalling £177,605 this year.

The AGM and conference were held again at the Woodland Grange, Leamington Spa. The conference was an opportunity to talk to others with similar conditions, to share advice and generally obtain a better understand of the conditions. It was also a rare opportunity to speak to health professionals who are researching and treating patients with myositis. The programme included updates on research and treatments as well as an open question and answer session. There was also time to talk to other members during lunch and perhaps new friendships formed. We are very grateful to the medical community who gave their time freely to attend. They are also very supportive of the charity

We have continued our membership of the National Council for Voluntary organisations and renewed our membership of the Fund-Raising Regulator. We continue our alliance with the Prescription Charges Coalition, BAD - British Association of Dermatologist patients support group, NORD - National organisation for rare disorders and the rare conditions network. We are also members of an alliance of patients' groups. Irene, our charity co-ordinator is a member of the working party and they have regular online meetings.

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For the Year Ended 31st March 2025

Chairman's review continued:

In September we were invited to attend the 25th Anniversary of the JDCBS (Juvenile Dermatomyositis Cohort Biomarker Study and Repository) held at the Institute for Child Health, UCL. The event featured insightful talks reflecting on JDCBS's growth and how standard healthcare practices in JDM have transformed over the years.

We attended the parent day at Great Ormond Street hospital for parents of children with JDM and we were invited to talk to them about the work of Myositis UK. We also attended the "Experimental Arthritis Treatment Centre for Children Showcase Event" at Alder Hey hospital where they highlighted some of the research they are undertaking for young people living with a rheumatic disease including myositis.

There are many people to thank too many by name in this report. However, without their support with their amazing fund raising activities we could never have the finances to promote the quest for a cure for all forms of myositis. There have also been legacies left by members to continue the work which has been humbling and heartening. I am sure that this year as in previous years has made another step forward in understanding and treating myositis.

Les Oakley MBE

Chairman

6th July 2025

Trustees Annual Report for the Year Ended 31st March 2025

The trustees of Myositis UK present their report & financial statement year ended 31st March 2025

Structure, Governance and Management

Nature of the Governing Document and Construction of the Charity

The charity is a registered charity, charity number 327791. The charity is governed by a constitution adopted 15th April 1988 and registered on 26th April 1988.

The methods adopted for the recruitment and appointment of new trustees

The Trustees shall retire annually but shall be eligible to offer themselves for re-election. Not less than 2 members may propose a member for election having first obtained the consent of such candidate. The Executive Committee can co-opt additional members from time to time to fill a vacancy or otherwise.

The organisational structure of the charity and how decisions are made

The Charity is managed by the Executive Committee consisting of the Chairman and General Secretary. The Trustees meet 3 times a year.

Decision making

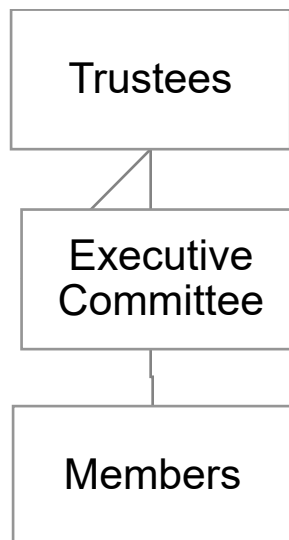
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

Risk management

The trustees have a duty to identify and review the risks to which the organisation is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error.

The Trustees are satisfied that systems are in place to mitigate the charity's exposure to the major risks. Policies and procedures are closely monitored. A key element in the management of financial risk is the setting of a reserves policy and its regular review.

The financial statements comply with current statutory requirements, the charity's trust deed and the statement of Recommended Practice - Accounting and Reporting by charities: SORP applicable to charities preparing their accounts in accordance with FRS 102.



Myositis UK - Charity Registration Number 327791

The Charity Principal Activities and Review of the Year Ended 31st March 2025

Objectives and Activities of the Charity

A summary of the objects of the charity as set out in its governing document

- To provide up to date information on all forms of Myositis
- To help give those affected a better understanding of their illness
- To relieve the isolation felt by the individual when a rare illness is diagnosed
- To guide those with the condition in the right direction of treatment
- To raise awareness of the conditions
- To raise funds to promote research

The charity's aims including the changes or differences it seeks to make through its activities.

We exist to help, advise and inform people with Myositis, but in addition to this basic function, we are trying to;

- Increase awareness of Myositis in the UK
- Generate good working relationships with the medical profession
- Improve communication for members
- Fund relevant research

Myositis UK - Charity Registration Number 327791

Achievements and Performance

Details of significant activities (including its main programmes, projects, or services provided) that contribute to the achievement of the stated objectives during 2024/2025

We continue to offer free membership to allow everyone access to information regardless of their circumstances. We would like to express our thanks to all the members and supporters who have donated or raised funds throughout the year. This support enables us to continue our work to advance the aims and objectives of the charity.

We continue to offer our website and community forum.

Members continued and took on challenges to fund raise for Myositis UK throughout the year.

The London Marathon Gold Bond purchased by the charity gave us 5 places each year for 5 years. The Marathon took place on the 21st April 2024 and our runners raised over £27,000. From 2026 the Gold Bond will only have 4 places instead of 5 and the cost per place will be £480. It was £444 per place.

New designs of Christmas cards were offered for sale 2024. We have a small stock left over, which will be offered for sale in 2025 along with new designs.

The advisory board forwarded their decisions to the Trustees for approval of one grant from the Large Grant scheme and four grants from the Small Grant Scheme. The trustees approved all five grants. One large grant of £97,724 to Professor Chinoy, Manchester. The four small grants were £19,973.70 to Dr Meredyth Wilkinson, UCL, £19,908.65 to Professor Pedro Machado, UCL, £20,000 to Dr Charalampia Papadopoulou, UCL and £20,000 to Dr. Paul Morgan, Manchester Metropolitan University.

The grant awarded to Dr Stefen Brady (John Radcliffe Hospital – Oxford) for £111,247.75, in May 2023 for “Optimism – Rapamycin for Inclusion Body Myositis” has still to be paid. This project involves Australia and countries in Europe. It is taking time for all the countries to be ready to start. This is being monitored, and we ask for regular updates for when this project will start.

The Grant schemes are advertised on our website twice a year. We have increased the amount of the small grants to £25,000 each and they were advertised in January 2025 with a closing date of March 2025. The advisory board have not yet forwarded their decisions to the Trustees.

The AGM and conference was held in July 2024 at the Woodland Grange, Leamington Spa. This was an in-person meeting and the feedback from members who did attend the conference was very positive. We will take into consideration this valuable feedback when organising the 2025 conference.

We have had many online meetings with various pharma companies who are showing an interest in Myositis. We have acted in an advisory capacity to inform them to understand how living with myositis affects our members day to day life. The charity received a small payment for our time.

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Financial Review – 2024-2025

In the year 2024-2025 total income was £140,081 of which £140,081 was unrestricted, there was no restrictive income in comparison in the year 2023-24 income was £262,343 of which £262,343 was unrestricted, there was no restrictive income.

Expenditure in 2024-25 total was £75,145 of which £75,145 was unrestricted, there was no restricted expenditure in comparison to the year 2023-24 expenditure was £230,706 of which £100,726 was unrestricted and £129,980 was restricted expenditure.

The detailed figures are included in the financial statements. At the year end the charity incurred a surplus of £64,936. A surplus of £468,781 was brought forward for the year 2024-25 leaving an unrestricted surplus to carry forward of £533,717. The restricted funds held at 31st March 2025 are £139,778.

The funds held at 31st March 2025

Unrestricted Fund £533,717

Restricted Funds £139,778

Total Funds 31st March 2025 £673,495

Fundraising Activities – 2024-2025

The London Marathon took place in April 2024. New Christmas cards were offered for sale this year. Merchandise was on sale at the conference. Supporters/members continued to fund raise for the charity, making donations & holding events.

Public Benefit Statement

The trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in the planning of future activities and setting the grant making policy for the year.

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2025

Public Benefit Statement

The trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in the planning of future activities and setting the grant making policy for the year.

Plans for Future Periods

For the period 2025/2026:

Attend meetings and conferences as appropriate throughout the year which have an interest in Myositis

- Continue with our main fund-raising activities – including the selling of Christmas cards for 2025
- Continue to maintain a good relationship with the medical profession
- Continue to support our members
- Continue to fund research
- Resume "Meet Ups" for members
- Facilitate zoom meetings for members with myositis specialists

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For the Year Ended 31st March 2025

Grants paid in the year ended 31st March 2025

Note: From unrestricted funds

GCOM Research Grant - Sara Sabbagh \$15,000

Paid 24/05/2024

The Medic College of Wisconsin 11,938.87

GCOM Research Grant - Christopher Nelke EU

14,026

Paid 23/05/24

Universitat Sklinkum 12,079.92

University of Manchester

Invoice 15145648

Paid 25/11/2025 12,750.00

36,768.79

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For the Year Ended 31st March 2025

Grants Approved, pending payment

Professor Lucy Wedderburn for the UK Juvenile Dermatomyositis Cohort & Biomarker Study £20,000 contribution towards the salary costs of the JDM Study Co-ordinator & £10,000 contribution towards the cost of consumables required for the study (approved January 2020). Extension granted to December 2025	30,000
Optimism – Rapamycin for Inclusion Body Myositis Dr Stefen Brady John Radcliffe Hospital – Oxford. Award, May 2023	111,247
Speed Funding GCOM 2024 “Rescue of TDP-43 function in in vitro and in vivo models of Inclusion Body Myositis (IBM)” Andrew Wilson Johns Hopkins University	12,000
A mitochondrial gene signature to stratify juvenile dermatomyositis patients for targeted treatments. Lead Researcher Dr Meredyth Wilkinson (University College London) awarded June 2024	19,973
MIRAGE: Myositis Inflammation Revealed through Advanced Magnetic Resonance Imaging Evaluation A Prospective Study. Professor Pedro Machado (University College London) awarded June 2024	19,908
The UK MYONET study: Increasing accuracy of autoantibody testing in myositis using new approaches and exploring genotype-autoantibody associations Professor Hector Chinoy (University of Manchester). Awarded December 2024.	97,724
Sleep disturbances and fatigue in children with Juvenile Dermatomyositis (JDM); do they relate to disease activity and pathology? Dr Charalampia Papadopoulou (University College London). Awarded: December 2024	20,000
Developing a dietary intervention to address muscle loss in inclusion body myositis (IBM). Dr Paul Morgan (Manchester Metropolitan University) Awarded: December 2024.	20,000
TOTAL	<u>330,852</u>

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For the Year Ended 31st March 2025

Reserves

The charity's unrestricted reserves are: £533,717

The Charity's restricted fund £139,778

Total funds held at 31st March 2025 £673,495

Reserves Policy

It is the policy of the charity to maintain unrestricted funds, which are the free reserves of the charity, at a level which can ensure the sustainability of the charity through periods of change, uncertainty and financial challenges. This is deemed necessary as a substantial part of the charity's funding is from fundraising and there is no certainty that the level of funding required to continue and develop the charity's activities will be received.

Going Concern

The board of Trustees are satisfied with the performance of the charity during the period and the position at 31st March 2025 and consider that the charity is in a good position to continue its activities during the coming year, and that the charity's assets are adequate to fulfil its obligations.

This report was approved by the Trustee's and signed on behalf of the Trustees by

Mr Leslie Oakley MBE (Charman)



Signature:

Full Name: Mr Leslie Charles Oakley, MBE

Position: Chairman Date: 06/07/2025

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2025

Independent Examiners Report

I report on the financial statements for the year ended 31st March 2025, which are set out on pages 13-19.

Respective responsibilities of trustees and examiner

The charity's trustees 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(2) of the Charities Act 2011 and that an independent examination is needed. I am qualified to undertake the examination by being a qualified member Associate Charity Independent Examiners.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act.
- to follow the procedures laid down in the General Directions given by the Charity Commission under section 145(5)(b) of the Act 2011; 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 seeking 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 material matters have come to my attention which give me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the 2011 Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Bridget Kalloushi Independent Examiner ACIE

B Kalloushi 6th July 2025

6, Linden Road

London

N10 3DH

Myositis UK – Charity Registration Number 327791

Balance Sheet as at 31st March 2025

	Notes	2025	2024
		£	£
FIXED ASSETS			
Tangible Assets		-	-
CURRENT ASSETS			
Cash at Bank & in hand		<u>703,495</u>	<u>641,988</u>
		703,988	641,988
CURRENT LIABILITIES			
Creditors: Amount fell due within one year		-	3,427
Accruals (page 10)		30,000	30,000
		<u>30,000</u>	<u>33,427</u>
NET CURRENT ASSETS		<u>673,495</u>	<u>608,561</u>
FUNDS			
General Fund		533,717	468,781
Restricted Funds (note 6)		<u>139,778</u>	<u>139,778</u>
TOTAL FUNDS		<u>673,495</u>	<u>608,559</u>

The notes on form part of these accounts

The accounts were approved by the Board of Trustees on 6th July 2025 and signed on its behalf by:

Les Oakley MBE
.....

Mr Leslie Charles Oakley MBE

Date 6th July 2025

Notes to the Accounts for the year ended 31st March 2025

Accounting policies

a. Basis of Preparing the Financial Statements

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: 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 I 02) (effective 1st January 2019) - (Charities SORP FRS 102). The charity meets the definition of a public benefit entity under FRS I 02. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b. Going Concern

The financial statements have been prepared on a going concern basis as the Trustees believe that no material uncertainties exist. The Trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure are sufficient with the level of reserves for the Charity to be able to continue as a going concern.

c. Cash Flow Statement

As a small charity the charity is not required to prepare a cash flow statement under the exemption under SORP (FRS I 02) for Charities with income of less than £500,000.

d. Income resources

All incoming resources are included in the Statement of Financial Activities when:

The charity is legally entitled to funds

There is sufficient certainty that receipt of the income is considered probable the amount can be reliably measured

Grants from Trusts and Donors are recognised as income in the SOFA in the year in which they are received. Any such income that is received for projects to be undertaken in future periods is carried forward as a restricted fund.

The Income and Expenditure account recognises the income applicable to the year's activities. Interest receivable is included when received by the Charity.

Notes to the Accounts for the year ended 31st March 2025

e Expenditure

As a non-company Charity expenditure is recognised on the accrual's basis under SORP (FRS 102). All costs which can be directly attributable to charitable activities are allocated thereto.

It is not considered that any purpose would be served in apportioning support costs (ie overheads, administration expenses and staff salaries) to particular charitable activities, as to do so would be arbitrary and could be misleading.

f Taxation

As a registered Charity (327791), it is exempt from taxation on investment income applied for Charitable purposes and from taxation on capital gains.

g Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued all the amount prepaid after taking account of any trade discount due.

j Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

k Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discount due.

l Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value, and subsequently measured at their settlement value.

m Significant Accounting Estimates and Judgements

The charity's estimates and assumptions are based on historical experience and expectation of future events and are reviewed annually.

Notes to the Accounts for the year ended 31st March 2025

n Fund Accounting

Unrestricted Funds are funds which can be used at the discretion of the Trustees in furtherance of the charity's objectives.

Restricted Funds are funds which can only be used for specific purposes as specified by the donor or when funds have been raised for a specific purpose.

o Debts and Guarantees

The charity has not given any guarantees where there is an outstanding liability at the date of this statement.

The charity has no outstanding debts at the date of this statement which are secured on the assets of the charity.

p Risk Management

The Trustees have identified and reviewed the major risks to which the charity is exposed on a regular basis. Systems have been established to mitigate these risks. Main risk with the continuing low interest rates the income from invested funds CAF has significantly decreased. We continue to exercise tight budgetary control on all our expenditure in order that all our income is used properly.

2. Trustees Remuneration & Expenses

No remuneration or expenses were paid to any Trustee or related party.

3. Staff Costs	2025	2024
Salaries (including ER Costs)	12,000	12,000

No employee received remuneration in excess of £60,000

Average number of employees 1

Administration/Development 1

Notes to the Accounts for the year ended 31st March 2025

4. Analysis of Cost of Raising Funds

	2025	2024
	£	£
Fundraising Activities		
London Marathon	2,700	1,980
Christmas Cards	1,280	1,239
Miscellaneous	-	727
Subscriptions	539	561
Total Raising Funds Activities Costs	£ <u>4,519</u>	<u>4,507</u>

5. Analysis of Cost of Charitable Activity

	2025	2024
	£	£
Research Costs - Note: unrestricted funds	36,768	51,662
Myositis UK Conference	7,327	8,480
GCOM Conference	-	8,980
Office Salary/Tax	12,000	12,000
Printing & Stationery	6,940	7,015
Postage	2,322	2,379
Telephone & Internet	1,068	1,122
Website	619	823
Office Equipment/Costs	3,000	492
Bank Charges	160	87
Miscellaneous Expenses	422	3,179
Total Payments for Charitable Activity	<u>70,626</u>	<u>96,219</u>
Total Resources Expended	£ <u>75,145</u>	<u>100,726</u>

The above expenditure has been directly allocated in accordance with the relevant restrictions.

Notes to the Accounts for the year ended 31st March 2025

6. Statement of Financial Activities – Analysis of Income

a	Unrestricted Funds	Restricted Funds	Total 2025	Unrestricted Fund	Restricted Fund	Total 2024
Grants/Legacies	31,544	-	31,544	140,726	-	140,726
Fundraising Activities	91,821	-	91,821	88,774	-	88,774
	£ 123,365	-	123,365	229,500	-	229,500

b Other Income Resources

Sundry Income	16,716	-	16,716	32,843	-	32,843
Total Funds	£ 140,081	-	140,081	262,343	-	262,343

7. Statement of Financial Activities – Analysis of Expenditure

	2025			2024		
Fund Raising Activities	4,519	-	4,519	4,507	-	4,507
Charitable activities	70,626	70,626	70,626	96,219	-	96,219
	£ 75,145	70,626	75,145	100,726	-	100,726









Myositis UK Trustees Report Financial Statements 2025_ Corrected

Final Audit Report

2025-08-23

Created:	2025-07-12
By:	Irene Oakley (irene@myositis.org.uk)
Status:	Signed
Transaction ID:	CBJCHBCAABAAAd3rwyq7qfhw5MhwG1qaxlv8ehDbckts5

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Signature Date: 2025-08-23 - 1:54:18 PM GMT - Time Source: server
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