

Myositis UK

Registered Charity Number: 327791



**Trustees Report and Financial Statements
For the year ended 31st March 2023**

Myositis UK

Trustees Report 2023

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Myositis UK - Charity Registration Number 327791

Reference & administrative Information

For the Year Ended 31st March 2023

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 2023

Chairman's review

It was only nine months ago that we held our last conference and I was presenting an annual review on the charity progress. We are now back on track with the issues of Covid causing many timing issues well behind us and I can now report of progress of the charity year.

The Global conference on Myositis held in Prague last June was taking place in the aftermath of the pandemic. It was a resounding success with Jiri Vencovsky and his team overcoming the mind-numbing setbacks in arranging the event caused by covid. They persevered and made it a thoroughly worthwhile international conference bringing all aspects of the myositis community together. We are pleased to have helped as an event bronze sponsor and also funded some of the poster prizes. There is no doubt Myositis UK has played its role in promoting international myositis meetings and the benefit these meeting bring. Of course, our mascot, Teddy-Bo, was in attendance who always creates much interest! The Global Conference was reported on in our Autumn 2022 magazine.

Myositis research has certainly moved on at a pace since our last conference and I am pleased to announce how these developments are taking place. I am grateful to Paul New who is based in Manchester for helping the charity as an administrator for these developments. You may recall the remarkable legacy from the late, Joyce Norman, has now been allocated to medical research after being peer reviewed by our Medical advisory board and Scientific Advisory committee along with the trustees of the charity. Four research projects have been agreed and are being supported with a total funding of £260,000.

It is also a pleasure to report on a successful 2022 London marathon with Team Muscle completing the course and enabling the charity to benefit from over £14,000 being raised. Brilliant result by a great and inspirational team of runners.

A charity is only as successful if its members or people associated with it making time a priority in their life for our cause. For this reason, I offer my thanks to everyone who has donated or fundraised throughout the year. This list of amazing individual activities to help are too much to mention in this report. However, there would be no advancement without this collective effort. People can be exceedingly kind in many ways and it never ceases to amaze me how much effort and time is given to our cause. I couple these remarks to all the medical profession too. We could be a wealthy charity but without their help and input progress would not be made in the manner it has.

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For the Year Ended 31st March 2023

Chairman's review continued:

The Myositis UK committee with our treasurer Jo Goode and charity auditor Bridget Kalloushi need to be congratulated in the effort and time they spend working in the background. They have all had serious long term health issues to contend with but have still managed to fulfil their role and keep the charity running and developing. As the charity progresses more work is created for everyone with new taxing challenges to overcome in keeping up with new developments. Behind the scenes of our charity are people such as Simon and Josephine Chadwick who produce our charity magazine, IT Computers for their technical support, volunteers who help in many ways, the medical and scientific teams around the country and Janet Horton for welfare advise. Keeping all these facets of charity activity and the centre hub for the coordination of these roles is my dear wife, Irene.

The next year will hopefully see developments fully on track with our attendance in person at a variety of meetings and conferences. For those who consider they are still vulnerable and perhaps travelling difficult, we will be introducing online meetings through Zoom that will be based on disease types.

Les Oakley MBE

Chairman

L C Oakley

23/07/2023

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Trustees Annual Report for the Year Ended 31st March 2023

The trustees of Myositis UK present their report & financial statement year ended 31st March 2023

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

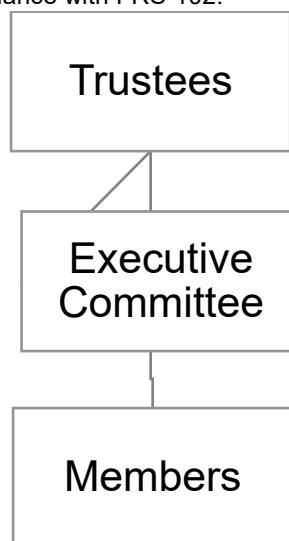
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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 2023

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

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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 2022/2023

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 allows us 5 places each year for 5 years. The Marathon took place on the 2nd October 2022 and our runners raised over £14,000.

New designs of Christmas Cards were offered for sale this year. We still have stock which will be offered for sale in 2023.

During 2022– 2023 our bear, “Teddy-Bo”, has slowly started to go on his travels again, He attended the GCOM conference in Prague and then went flying in Germany. Photos will be in the summer “Myositis News”. Hopefully, he will continue travelling to help raise awareness of the charity and Myositis.

It was hoped to arrange the AGM and conference in July but we were unable to hold it until October. This was an in-person meeting and the feedback from members who did attend the conference was very positive. This was the first in person meeting held since Covid.

The Myositis UK - Scientific Advisory Committee (SAC) reviewed an application from the Manchester Myositis Research Team (Dr Janine Lamb and Prof Hector Chinoy). They have approved their request for £10,520 to extract DNA from the remaining 600 UKMYONET blood samples for collaboration with Regeneron, a genetic company. The trustees agreed to this funding.

The Small Grant scheme was advertised on our website in November offering two grants of £10,000. The closing date for applications was 1st March 2023. We also advertised a Large Grant scheme in Inclusion Body Myositis with £260,000 available. Paul New, Myositis Grant co-ordinator, oversaw the whole process. The advisory boards will forward their decisions to the Trustees for approval.

The charity has been offered a stand at the British Society of Dermatology Conference in June 2023. This will be an opportunity to inform Dermatology of the charity. This is a three-day conference and Irene and Les Oakley will be attending.

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Financial Review – 2022-2023

In the year 2022-2023 total income was £115,653 of which £115,653 was unrestricted, there was no restrictive income in comparison in the year 2021-22 income was £85,177 of which £85,177 was unrestricted, there was no restrictive income.

Expenditure in 2022-23 total was £68,810 of which £68,810 was unrestricted there was no restricted expenditure in comparison in the year 2021-22 expenditure was £18,757 of which £18,757 was unrestricted, there was no restricted expenditure.

The detailed figures are included in the financial statements. At the year end the charity incurred a surplus of £46,843. A surplus of was £260,321 brought forward for the year 2021-22 leaving an unrestricted surplus to carry forward of £ 307,164. The restricted funds held at 31st March 2023 are £269,758.

The funds held at 31st March 2023

Unrestricted Fund £307,164

Restricted Funds £269,758

Total Funds 31st March 2022 £ 576,922

Fundraising Activities – 2022-2023

The London Marathon took place in October 2022. New Christmas cards were offered for sale this year. Merchandise was on sale at the conference. Supporters/members continued to fun raise for the charity, making donations & holding events.

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For the Year Ended 31st March 2023

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 2023/2024:

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 2023
- 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

Grants paid in the year ended 31st March 2023

Congress Prague – GCOM Conference Sponsor	10,505
University College London – part payment Prof. Pedro Machado	7,200
Manchester University – Professor Hector Chinoy/ Dr Janine Lamb	23,162
	<hr/>
	£ 40,867

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For the Year Ended 31st March 2023

Grants Approved, pending payment

Dr Pedro Machado for IBM AD amyloid PET imaging, at his request had an extension approved by the trustees until 31 st December 2020 (approved October 2017). Total Grant £12,000. £7,200 paid balance:	4,800
Database manager for four months for the IMACS core set measures online training tool. Dr Hector Chinoy & Dr James Lilleker, The University of Manchester & Prof Raashid Luqmani, University of Oxford (approved January 2019).	5,000
Salary of Experimental Officer Hazel Platt for six months at The Faculty of Biology, Medicine and Health, University of Manchester has been extended until 30 th June 2022 (approved June 2019). Extension granted to end June 2023	12,800
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
	£ <u>52,600</u>

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For the Year Ended 31st March 2023

Reserves

The charity's unrestricted reserves are: £307,164

The Charity's restricted fund £269,758

Total funds held at 31st March 2023 £576,922

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 2023 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)

L C Oakley

Signature:

Full Name: Mr Leslie Charles Oakley, MBE

Position: Chairman Date: 23/07/2023

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For the Year Ended 31st March 2023

Independent Examiners Report

I report on the financial statements for the year ended 31st March 2023, which are set out on pages 12-18.

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

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6, Linden Road

London

N10 3DH

Myositis UK – Charity Registration Number 327791

Balance Sheet as at 31st March 2023

	Notes	2023	2022
		£	£
FIXED ASSETS			
Tangible Assets		-	-
CURRENT ASSETS			
Debtors			
Cash at Bank & on Deposit		<u>629,522</u>	<u>589,879</u>
CURRENT LIABILITIES			
Income in Advance		-	-
Accruals (page 9)		52,600	59,800
Amounts falling due within one year		_____	_____
NET CURRENT ASSETS		<u>576,922</u>	<u>530,079</u>
FUNDS			
General Fund		307,164	260,321
Restricted Funds (note 6)		<u>269,758</u>	<u>269,758</u>
TOTAL FUNDS		<u>576,922</u>	<u>530,079</u>

The notes on form part of these accounts

The accounts were approved by the Board of Trustees on 23rd July 2023 and signed on its behalf by:

LC Oakley

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Mr Leslie Charles Oakley MBE

Date 23/07/2023

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2023

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.

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Notes to the Accounts for the year ended 31st March 2023

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.

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Notes to the Accounts for the year ended 31st March 2023

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	2023	2022
Salaries (including ER Costs)	12,000	11,917

No employee received remuneration in excess of £60,000

Average number of employees 1

Administration/Development 1

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Notes to the Accounts for the year ended 31st March 2023

4. Analysis of Cost of Raising Funds

	2023	2022
	£	£
Fundraising Activities		
London Marathon	1,980	1,980
Christmas Cards	1,268	-
Miscellaneous	967	687
Subscriptions	558	-
Total Raising Funds Activities Costs	£ 4,773	2,667

5. Analysis of Cost of Charitable Activity

	2012	2022
	£	£
Research Costs	33,667	-
Myositis UK Conference	6,738	-
GCOM Conference	1,726	-
Office Salary/Tax	12,000	11,917
Printing & Stationary	3,518	955
Postage	1,302	1,231
Telephone & Internet	774	820
Website	240	-
Office Equipment/Costs	2,278	794
Bank Charges	103	170
Miscellaneous Expenses	1,691	203
Total Payments for Charitable Activity	64,037	16,090
Total Resources Expended	£ 68,810	18,757

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

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Notes to the Accounts for the year ended 31st March 2023

6. Statement of Financial Activities – Analysis of Income

a	Unrestricted Funds	Restricted Funds	Total 2023	Unrestricted Fund	Restricted Fund	Total 2022
Grants/Legacies	37,000	-	37,000	-	269,758	269,758
Other Donations/ Fundraising Activities	74,958	-	74,958	84,694	-	84,694
	£ 111,958	-	111,958	84,694	269,758	354,452

b Other Income Resources

Sundry Income	3,695	-	3,695	483	-	483
	£ 115,653	-	115,653	85,177	269,758	354,935