

MYOSITIS UK

England & Wales · Charity number 327791

Details

Other names	MYOSITIS SUPPORT GROUP, THE DERMATOMYOSITIS AND POLYMYOSITIS SUPPORT GROUP
Status	Registered
Legal form	Other
Registered	1988-04-26
Register	View on the Charity Commission register

Contact

Address	146 Newtown Road Southampton SO19 9HR
Phone	023 8044 9708
Email	msg@myositis.org.uk
Website	www.myositis.org.uk

Activities

Objects: TO PROMOTE THE RELIEF OF PERSONS SUFFERING FROM DERMATOMYOSITIS AND POLYMYOSITIS AND THEIR FAMILIES AND TO SUPPORT AND PROMOTE MEDICAL RESEARCH INTO THE SEARCH FOR A CURE FOR AND FOR BETTER TREATMENT OF THE DISEASES INCLUDING THE PROVISION OF FUNDS AND EQUIPMENT TO SUFFERERS AND THEIR FAMILIES AND TO MEDICAL RESEARCH.

Activities: 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 and fund research

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, Other Charities Or Voluntary Bodies

Geography

- Northern Ireland
- Scotland

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£140,081	£75,145	-	-
2024-03-31	£262,343	£230,706	-	-
2023-03-31	£115,653	£68,810	-	-
2022-03-31	£85,177	£18,757	-	-
2021-03-31	£347,239	£152,570	-	-

Trustees

Name	Role	Appointed
LESLIE CHARLES OAKLEY MBE	Chair	
JOANNE DEBORAH GOODE		
PAULA RACHAEL JORDAN		

MYOSITIS UK

England & Wales - Charity number 327791

Accounts

Myositis UK

Registered Charity Number: 327791



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

Myositis UK

Trustees Report 2025

Contents:	Page
Reference & Administrative Details	1
Chairs Review	2-3
Trustees Report	4-11
Independent Examiners Report	12
Statement of Financial Activities	13
Balance Sheet	14
Notes to the Accounts	15-19

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

Myositis UK - Charity Registration Number 327791

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.

Myositis UK - Charity Registration Number 327791

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

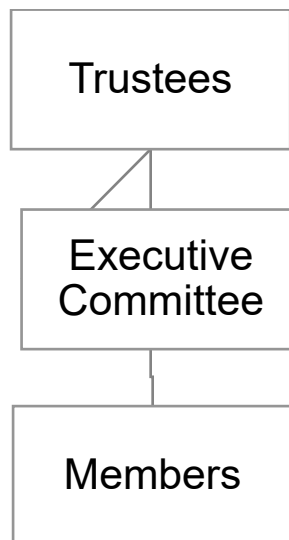
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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.

Myositis UK - Charity Registration Number 327791

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

Myositis UK - Charity Registration Number 327791

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

Myositis UK - Charity Registration Number 327791

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>

Myositis UK - Charity Registration Number 327791

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
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"Myositis UK Trustees Report Financial Statements 2025_ Corrected" History


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

 Agreement completed.
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MYOSITIS UK

England & Wales - Charity number 327791

Accounts

Myositis UK

Registered Charity Number: 327791



**Trustees Report and Financial Statements
For the year ended 31st March 2024**

Myositis UK

Trustees Report 2024

Contents:	Page
Reference & Administrative Details	1
Chairs Review	2-4
Trustees Report	5-11
Independent Examiners Report	12
Statement of Financial Activities	13
Balance Sheet	14
Notes to the Accounts	15-19

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Reference & Administrative Information

For the Year Ended 31st March 2024

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

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2024

Chairman's review

Through the years it has never been a problem to highlight the work and the activities of the membership and friends of the charity. This year is no exception with much having successfully taken place and a pleasure to report on.

One of the events at the beginning of the year was the London Marathon on Sunday 23rd April 2023. The six runners of "Team Muscle" who took part raised over £8,000 for the charity. Three of the runners and their families and friends found us in the park and it was great to meet them and to thank them all for the effort they made to help us. These moments of friendship make all the work worthwhile. This as in previous years was again a brilliant result by a great and inspirational team of runners.

In June 2023 Myositis UK funded a grant of £5,000 to the European Neuro Muscular Centre in the Netherlands and Myositis UK is a co-funder of a workshop on Inclusion Body Myositis – *Ten years of progress – revision of the "ENMC 2013 diagnostic criteria for IBM" and trial readiness*. There were twenty-nine participants from many countries including three from the UK. This workshop has now produced updated criteria for IBM worldwide. *We also co-funded the 2013 workshop!*

In June Myositis UK had a stand at the 103rd Annual Meeting of the British Association of Dermatology in Liverpool. This was the first time we had attended this meeting. It was a very interesting few days and many delegates came to our stand where we were able to inform them of our work as a charity. Many of the large pharma companies were there and we were able to collect samples of creams to give away at our conference in July. Whilst we were at the conference, we had a meeting with Dr Jennifer Hall from Adelphi Real World who were interested in attending our conference in July to host a short session to explore what support currently exists for patients and caregivers. It was agreed for them to attend.

Myositis research has continued to move at pace again this year. Three of the four grants reported in last year's report have now been paid and are up and running. There is still one of these grants outstanding. Sometimes they do take longer to set up than perhaps we would like. In the second round of grants in September 2023 the medical advisory board and scientific advisory committee only recommended funding one grant of £20,000 for Baricitinib Study. This was to Dr Janine Lamb – University of Manchester and has been paid and is up and running.

We had a change of venue for the AGM and conference held in July 2023. It was held at the Woodland Grange, Leamington Spa. There were two reasons for moving from Oxford. One to make it more central for members to attend from across the country and the other was that we had a few behind the scenes issues with the previous venue. The staff at the Woodland Grange were extremely helpful and accommodating. 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 those in the medical community who gave their time freely to attend.

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2024

Chairman's review continued:

Myositis UK is now an NIHR non-commercial partner (National Institute for Health research). This means the studies that we fund may be eligible to access the NIHR study support service which is provided by the NIHR Clinical Research Network within the NHS and the wider public health and social care environment across England

Myositis UK is now an NIHR non-commercial partner (National Institute for Health research). This means the studies that we fund may be eligible to access the NIHR study support service which is provided by the NIHR Clinical Research Network within the NHS and the wider public health and social care environment across England.

We have continued to work throughout the year with various pharmaceutical companies who have an interest in Myositis. Two of these companies were looking for patients who may be suitable for their drug trials. 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 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 had a paper published titled '*Working towards a patient-centred Global Myositis Alliance: call for partnership.*' Irene attended a consensus meeting in Rotterdam in September looking at the prospect of a clinical trial in JDM within Europe and the UK. A follow up zoom meeting was held in January.

In October we (Les & Irene Oakley, Jo Goode) attended the UK Myonet meeting in London. A variety of presentations were given and the afternoon rounded off with an enthusiastic debate covering the day's agenda. This was the first time UK Myonet had met since Covid. As an observer sat at the back of the room it was a pleasure to witness this event and to see how hard these people work behind the scenes in attempting to improve the quality of life for all myositis patients. Myositis UK sponsored the cost of the room for this meeting.

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2024

Chairman's review continued:

World Myositis Day was founded by representatives of various international myositis groups and organisations from Australia, Canada, Czech Republic, Germany, Sweden, The Netherlands, United Kingdom and the United States of America. The first world myositis day was on the 21st of September 2023. This special day will be celebrated every year on September the 21st from now on.

The 5th global conference on myositis was held in Pittsburgh, USA from the 13th to the 16th of March 2024 since the first conference held in Stockholm in 2015 followed by further conferences in the USA, Berlin and Prague. This conference has firmly established its place in the field of myositis research. Myositis UK has participated at all the four previous GCOM conferences. In particular the charity funded the speed funding in Berlin which was a great success and has been well reported in previous editions of Myositis News. The trustees agreed to fund the speed funding at GCOM 2024 where young scientists or investigators were encouraged to apply for a maximum of two years funding of \$15,000 for research projects in the field of myositis. Seven of these young scientists were chosen to present at the GCOM meeting and three were awarded funding of \$15,000 for their research projects 2024-2025. The quality of the presentations were excellent and it must have been very difficult for the judges to decide on the three best projects. We also had a stand at the meeting and were able to talk to many of the delegates there and to other patients support groups. Included in the main programme there was a session where patients presented their own story. Patient group representatives also gave presentations and Myositis UK was delighted to talk on the speed funding and how important funding research is to myositis patients.

Les Oakley MBE

Chairman

LC Oakley

14/07/2024

Myositis UK - Charity Registration Number 327791

Trustees Annual Report for the Year Ended 31st March 2024

The trustees of Myositis UK present their report & financial statement year ended 31st March 2024

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

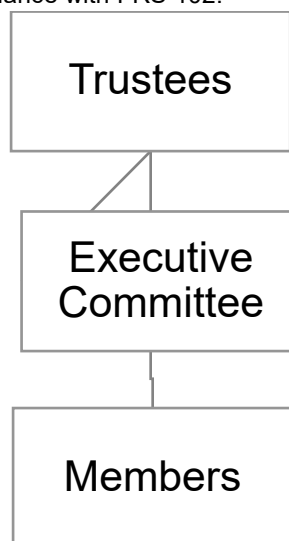
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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 2024

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 2023/2024

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 23rd April 2023 and our runners raised over £8,000.

No new designs of Christmas Cards were offered for sale this year. We still had stock from 2022. New designs will be offered for sale in 2024.

The advisory board forwarded their decisions to the Trustees for approval of two grants from the Large Grant scheme in Inclusion Body Myositis and two grants from the Small Grant Scheme. The trustees approved all four grants. One large grant of £129,797 to Professor Machado, UCL has been paid. The grant of £111,247 to Dr. Brady, Oxford has not yet been paid. The small grant of £9,998.37 to Dr Ali, King's College has been paid. The small grant of £9,680 to Dr S Varakliotis, GOSH has been paid.

During 2023–2024 our bear, “Teddy-Bo”, has continued on his travels again, He attended a meeting in Rotterdam and the GCOM conference in Pittsburgh, USA. He will continue travelling to help raise awareness of the charity and Myositis.

The AGM and conference was held in July 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.

The Small Grant scheme was advertised on our website in September 2023 offering two grants of £20,000. There were several applications but only one was recommended to fund by the advisory board. The trustees approved the grant of £20,000 to Dr Lamb, Manchester which has been paid.

The trustees agreed to offer travel bursaries to young doctors/researchers from the UK who had a presentation or poster accepted for GCOM in Pittsburgh. Travel bursaries were also offered to the seven applicants selected to present their research projects for the speed funding at GCOM. Myositis UK was offering three research grants of 15,000 US Dollars to the successful applicants. This sponsorship gave Myositis UK the recognition as a main sponsor of the conference which raised the profile of the charity and our logo on all conference material. We also had a booth in the exhibition hall.

The charity had a stand at the British Society of Dermatology Conference in June 2023. This gave us the opportunity to inform Dermatology of the charity. This was a three-day conference and Irene and Les Oakley attended.

Two grants of £20,000 were advertised in January 2024 with a closing date of March 2024. The advisory board have not yet forwarded their decisions to the Trustees.

Myositis UK - Charity Registration Number 327791

Financial Review – 2023-2024

In the year 2023-2024 total income was £262,343 of which £262,343 was unrestricted, there was no restrictive income in comparison in the year 2022-23 income was £115,653 of which £115,653 was unrestricted, there was no restrictive income.

Expenditure in 2023-24 total was £230,706 of which £100,726 was unrestricted £129,980 was restricted, expenditure in comparison in the year 2022-23 expenditure was £68,810 of which £68,810 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 £161,617. A surplus of £307,164 was brought forward for the year 2022-23 leaving an unrestricted surplus to carry forward of £468,781. The restricted funds held at 31st March 2024 are £139,778.

The funds held at 31st March 2024

Unrestricted Fund £468,781

Restricted Funds £139,778

Total Funds 31st March 2024 £608,559

Fundraising Activities – 2023-2024

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.

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2024

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 2024/2025:

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 2024
- 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 2024

Note: From unrestricted funds

Kings College London – Myoact Registrar	9,999
University Of Manchester – Baricitinib Study	20,000
Great Ormond Street - Dr Sakratis Varakiotis	9,680
University of Manchester – BSR Advance Funding	6,983
ENMC Workshop – IBM	5,000
	<hr/>
	£ 51,662

Note: From restricted Fund

University College London – IBM Disease Pathways Study	£ 129,797
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Myositis UK - Charity Registration Number 327791
For the Year Ended 31st March 2024

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
	<u>£ 30,000</u>

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2024

Reserves

The charity's unrestricted reserves are: £468,781

The Charity's restricted fund £139,778

Total funds held at 31st March 2024 £608,559

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 2024 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: 14/07/2024

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2024

Independent Examiners Report

I report on the financial statements for the year ended 31st March 2024, 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

Bridget Kalloushi

14th July 2024

6, Linden Road
London N10 3DH

Myositis UK – Charity Registration Number 327791

Balance Sheet as at 31st March 2024

	Notes	2024	2023
		£	£
FIXED ASSETS			
Tangible Assets		-	-
CURRENT ASSETS			
Cash at Bank & in hand		<u>641,988</u>	<u>629,522</u>
		641,988	629,522
CURRENT LIABILITIES			
Creditors: Amount fell due within one year		3,427	-
Accruals (page 10)		30,000	52,600
		<u>33,427</u>	<u>52,600</u>
NET CURRENT ASSETS		<u>608,561</u>	<u>576,922</u>
FUNDS			
General Fund		468,781	307,164
Restricted Funds (note 6)		<u>139,778</u>	<u>269,758</u>
TOTAL FUNDS		<u>608,559</u>	<u>576,922</u>

The notes on form part of these accounts

The accounts were approved by the Board of Trustees on 14th July 2024 and signed on its behalf by:

L C Oakley

.....

Mr Leslie Charles Oakley MBE

Date 14/07/2024

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2024

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.

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2024

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.

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2024

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	2024	2023
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

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2024

4. Analysis of Cost of Raising Funds

	2024	2023
	£	£
Fundraising Activities		
London Marathon	1,980	1,980
Christmas Cards	1,239	1,268
Miscellaneous	727	967
Subscriptions	561	558
Total Raising Funds Activities Costs	£ <u>4,507</u>	<u>4,773</u>

5. Analysis of Cost of Charitable Activity

	2024	2023
	£	£
Research Costs - Note: unrestricted funds	51,662	33,667
Myositis UK Conference	8,480	6,738
GCOM Conference	8,980	1,726
Office Salary/Tax	12,000	12,000
Printing & Stationary	7,015	3,518
Postage	2,379	1,302
Telephone & Internet	1,122	774
Website	823	240
Office Equipment/Costs	492	2,278
Bank Charges	87	103
Miscellaneous Expenses	3,179	1,691
Total Payments for Charitable Activity	<u>96,219</u>	<u>64,037</u>
Total Resources Expended	£ <u>100,726</u>	<u>66,810</u>

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

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2024

6. Statement of Financial Activities – Analysis of Income

a	Unrestricted Funds	Restricted Funds	Total 2024	Unrestricted Fund	Restricted Fund	Total 2023
Grants/Legacies	140,726	-	140,726	37,000	-	37,000
Other Donations/ Fundraising Activities	88,774	-	88,774	74,958	-	74,958
	<hr/>					
£	229,500	-	229,500	111,958	-	111,958
	<hr/>					

b Other Income Resources

Sundry Income	32,843	-	32,843	3,695	-	3,695
	<hr/>					
Total Funds	£ 262,343	-	262,343	115,653	-	115,653
	<hr/>					

7. Statement of Financial Activities – Analysis of Expenditure 2024

Fund Raising Activities	4,507	-	4,507	4,773	-	4,773
Charitable activities	96,219	129,980	226,199	64,037	-	64,037
	<hr/>					
£	100,726	129,980	230,706	68,810	-	68,810
	<hr/>					

MYOSITIS UK

England & Wales - Charity number 327791

Accounts

Myositis UK

Registered Charity Number: 327791



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

Myositis UK

Trustees Report 2023

Contents:	Page
Reference & Administrative Details	1
Chairs Review	2-3
Trustees Report	4-10
Independent Examiners Report	11
Statement of Financial Activities	12
Balance Sheet	13
Notes to the Accounts	14-18

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

Myositis UK - Charity Registration Number 327791

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.

Myositis UK - Charity Registration Number 327791

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

Myositis UK - Charity Registration Number 327791

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

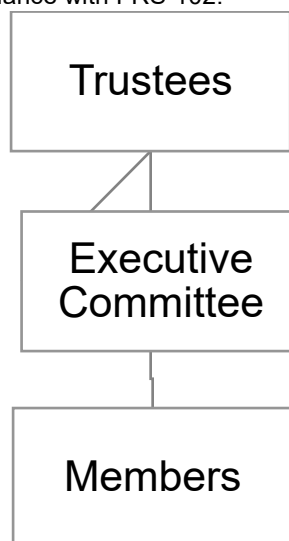
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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

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 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.

Myositis UK - Charity Registration Number 327791

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.

Myositis UK - Charity Registration Number 327791

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

Myositis UK - Charity Registration Number 327791

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>

Myositis UK - Charity Registration Number 327791

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

Myositis UK - Charity Registration Number 327791

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

.....

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

.....

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.

Myositis UK - Charity Registration Number 327791

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.

Myositis UK - Charity Registration Number 327791

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

Myositis UK - Charity Registration Number 327791

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.

Myositis UK - Charity Registration Number 327791

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

MYOSITIS UK

England & Wales - Charity number 327791

Accounts

Myositis UK

Registered Charity Number: 327791



Trustees Report and Financial Statements

For the year ended 31st March 2022

Myositis UK

Trustees Report 2022

Contents:	Page
Reference & Administrative Details	1
Chairs Review	2-3
Trustees Report	4-10
Independent Examiners Report	11
Statement of Financial Activities	12
Balance Sheet	13
Notes to the Accounts	14-18

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2022

Chairman's review

Although we were still experiencing some of the restricting issues of Covid-19 during the year it has not prevented the charity from operating. There is also no doubt that Trustee and treasurer, Jo Goode, who facilitates her Face Book Page Myositis Community of Great Britain and Ireland has greatly reduced the isolation of people having to live and cope with myositis. Members, family and friends have during the year tirelessly raised funds for which we are incredibly grateful. Our London marathon team continued to train, being focussed on not only the running, but having the myositis cause as the motivation for their effort and determination. This event for Team Muscle took place on Sunday 3rd of October and raised over £11,000 for the charity.

During this period, it has been difficult for the trustees to make financial decisions when considering the next steps to take to advance progress in myositis particularly in medical research. Irene and I are well aware that we are getting on in years and time waits for nobody! Our lifetime ambition has been to see myositis in all its forms as a group of diseases that can be successfully managed or even, dare I say, cured.

As I reported last year at the end of 2019 the charity was informed that it was a major beneficiary of the estate of the late Joyce Winifred Norman. She kindly and quietly bequeathed the charity £269,772.71 which the charity received in March 2020. This is the largest gift the charity has ever received, and the trustees were stunned to hear this news. We realised that we could now consider expanding medical research and after being on the back foot the emphasis was now on the front one. Joyce wished that this money be spent on Inclusion Body Myositis in memory of her husband who died from IBM. In agreement with her wishes this we will do. But what this also means is the charities existing funds can be allocated to the other diseases we support and give them a boost too.

As a result of this wonderful gift the trustees have needed to consider how we manage and determine developments in myositis research. Zoom meetings were held with the trustees, researchers and doctors to establish two panels of experts. One a medical panel and the other a scientific panel. These panels will oversee and consider future projects. Their recommendations will then be put to the trustees in any decision making.

As a result of this meeting two Advisory boards have now been formed. A medical Advisory Board (MAB) consisting of four members and a Scientific board consisting of seven members. It was agreed that this was the way forward and the medical profession could be acknowledged for their individual input and for their involvement in the progress of myositis research. It also means that as the charity has a recognised medical structure, we can work with other grant funders as equal partners to facilitate a larger project if the opportunity arises.

This wonderful development has been possible by the sheer kindness of Joyce who valued the charity worthy of this gift. We cannot personally say thank you to her, but we can make this gift work in memory of her and perhaps it will create another great step forward in beating this disease.

Page 2

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2022

We were still unable to hold any meetings in person again this year. In 2022 we will be holding our AGM and conference in person again.

We still had a small stock of Christmas cards, so no new cards were ordered. These were offered for sale at a reduced price. These were all sold so new designs will be available in 2022.

The 4th Global Conference on Myositis will be held in Prague in June 2022, and we will again look to be sponsors at this event.

Due to the large number of charity places carried over due to the Covid pandemic the London Marathon decided to buy back some of these places. Each charity was informed of the number of places to be brought back and we received back payment for six places. This left us twelve places for 2022.

I would like to thank all who raised funds for the charity whether they are members, family, friends or our medical teams. To read and follow these wonderful people in their efforts has been amazing and very heartening. These events and projects have been well reported by the charity and deservedly published in our Charity News magazine and on our relevant web pages. I am particularly grateful to members, family and friends who have donated in memory of loved ones and to those who donated money in celebrating a special family occasion.

My appreciation is offered to the medical teams and their support staff for their tireless energy in helping our members with these miserable conditions, especially during these difficult times.

All charities need committed and dedicated people to make the charity realise its aims and ambition. Our trustees have worked very hard in what can appear to be a thankless task. Treasurer, Jo Goode, is quite remarkable in all her efforts associated with the charity. Auditor, Bridget Kalloushi, has given her time in overseeing our accounts. The charity's association with Simon Chadwick, who produces our news magazine, is very much appreciated.

Les Oakley MBE

Chairman

L C Oakley

16th October 2022

Page 3

Myositis UK - Charity Registration Number 327791

Trustees Annual Report for the year ended 31st March 2022

**The trustees of Myositis UK present their report & financial statement
year ended 21st March 2022**

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

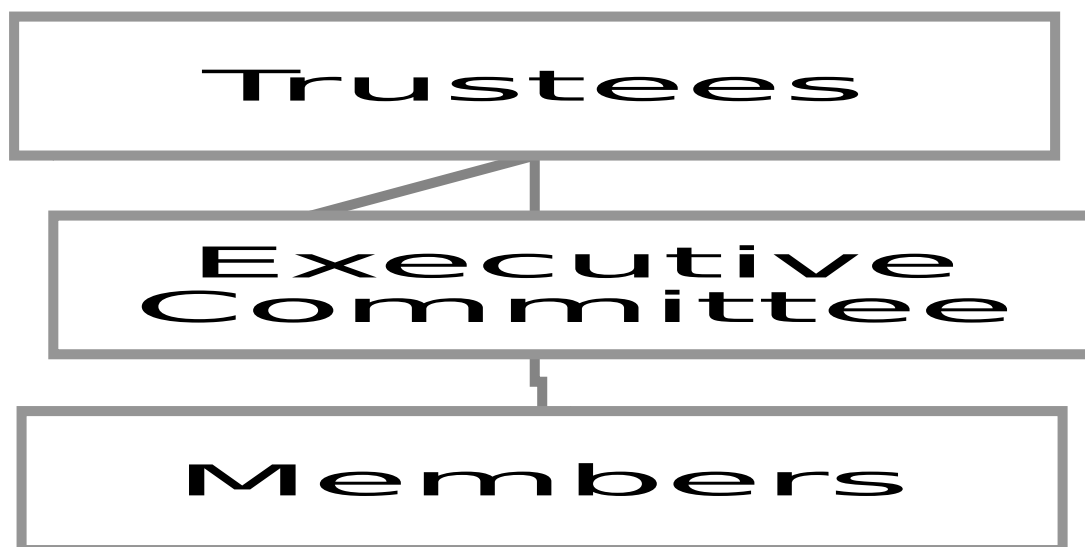
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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.



Page 4

**Myositis UK - Charity Registration Number
327791**

**The Charity Principal Activities and Review of the
Year Ended 31st March 2022**

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

Page 5

Myositis UK - Charity Registration Number 327791

Achievements and Performance For the Year Ended 31st March 2022

Details of significant activities (including its main programmes, projects, or services provided) that contribute to the achievement of the stated objectives during 2021/2022

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, Helen Kurtz continued "Helen's Fibre 4 Fibres Fundraiser" 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 3rd October 2021 and our runners raised over £11,000.

This year we were unable to hold the Christmas Draw, but were able to sell Christmas

Cards.

During 2021 - 2022 our bear, "Teddy-Bo", has not been on any travels, so no new photographs have been taken, but hopefully he will continue travelling in the future to help raise awareness of the charity and Myositis.

The AGM was arranged as a Zoom meeting to be held on Sunday 23rd January 2021 at 11am. This was cancelled due to unforeseen circumstances. The AGM took place on Sunday 26th June 2022.

Due to the Covid 19 pandemic there were no in person meetings to attend.

Zoom meetings were held to discuss the formation of a Medical Advisory Board and A Scientific Board to develop a structured form for grant applications and to advise the trustees on any applications for funding.

Page 6

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2022

Financial Review - 2021-2022

In the year 2021-2022 total income was £85,177 of which £85,177 was unrestricted, there was no restrictive income in comparison in the year 2020-21 income was £347,239 of which £77,481 was unrestricted and restricted income £269,758.

Expenditure in 2021-22 total was £18,757 of which £18,757 was unrestricted there was no restricted expenditure in comparison in the year 2020-21 expenditure was £152,570 of which £152,570 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 £66,420. A surplus of was £193,901 brought forward for the year

2020-21 leaving an unrestricted surplus to carry forward of £260,321. The restricted funds held at 31st March 2022 are £269,758.

The funds held at 31st March 2022

Unrestricted Fund	260,321
Restricted Funds	<u>269,758</u>
Total Funds 31 st March 2022	£ <u>530,079</u>

Fundraising Activities - 2021-2022

The London Marathon took place in October 2021 The remaining stock of Christmas cards were offered for sale this year (December 22). Supporters/members continued to fun raise for the charity, making donations & holding events.

Page 7

**Myositis UK - Charity Registration Number
327791**

For the Year Ended 31st March 2022

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 2022/2023:

The Covid 19 pandemic will have an effect on what will be possible in the coming year but we would hope to:

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

- o Continue with our main fund-raising activities - including the selling of Christmas cards for 2021
- o Continue to maintain a good relationship with the medical profession
- o Continue to support our members
- o Continue to fund research

Grants paid in the year ended 31st March 2022

No grants paid during period 2021-22 (due to covid restrictions postponing medical research)

**Myositis UK - Charity Registration Number
327791**

For the Year Ended 31st March 2022

Grants Approved, pending payment

Dr Pedro Machado for IBM AD amyloid PET imaging, at his request had an extension approved by the trustees until 31st December 2020 (approved October 2017). 12,000

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 30th June 2022 (approved June 2019). 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). 30,000

59,800

_____ £

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2022

Reserves

The charity's unrestricted reserves are: £260,321

The Charity's restricted fund £269,758

Total funds held at 31st March 2022 £530,079

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 2022 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

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2022

Independent Examiners Report

I report on the financial statements for the year ended 31st March 2022, 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

..... date

6, Linden Road London N10 3DH

Page 11

Myositis UK - Charity Registration Number 327791

For the Year Ended 31st March 2022

Statement of Financial Activities for the year ended 31st March 2022

	Note	General Fund £	Restricted Funds £	2022 Total £	Unrestricted Funds £	Restricted Funds £	2021 Total £
INCOME AND ENDOWMENT FORM							
Donations, Grants		72,510	271,758	344,268	21,384		21,384
Fund Raising Activities					45,019		45,019
Other Income Resources		3,755		3,755	2,096		2,096
TOTAL INCOMING RESOURCES		<u>76,265</u>	<u>271,758</u>	<u>348,023</u>	<u>68,499</u>	<u>0</u>	<u>68,499</u>
EXPENDITURE ON							
Fund Raising Activities		2,661			3,458		3,458
Charitable Activities		90,114	0		60,213		60,213
TOTAL RESOURCES EXPENDED		<u>92,775</u>	<u>271,758</u>	<u>92,766</u>	<u>63,671</u>	<u>0</u>	<u>63,671</u>
NET INCOME/ (EXPENDITURE)	(16,510)				4,738		4,738
Before Transfer							
NET MOVEMENT IN FUNDS	(16,510)		0	0	4,738	0	4,738
Total Funds brought forward at 31st March 2021		268,990			264,252		264,252
TOTAL FUNDS carried forward at 31st March 2022		<u>252,480</u>	<u>271,758</u>	<u>524,238</u>	<u>268,990</u>	<u>0</u>	<u>268,990</u>

The notes form part of these accounts

Myositis UK - Charity Registration Number 327791

Balance Sheet as at 31st March 2022

	Notes	2022	2021
		£	£
FIXED ASSETS			
Tangible Assets		-	
-			
CURRENT ASSETS			
Debtors		-	
-			
Cash at Bank & on Deposit		<u>589,879</u>	<u>524,238</u>
CURRENT LIABILITIES			
Income in Advance		-	
779			
Accruals (page 9)		59,800	
59,800			
Amounts falling due within one year		_____	-

NET CURRENT ASSETS		<u>530,079</u>	<u>463,659</u>
FUNDS			
General Fund		260,321	
193,901			
Restricted Funds (note 6)		<u>269,758</u>	<u>269,758</u>
TOTAL FUNDS		<u>530,079</u>	
<u>463,659</u>			

The notes on form part of these accounts

The accounts were approved by the Board of Trustees on 23/07/2023 and signed on its behalf by:

L C Oakley

.....

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2022

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.

Page 14

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2022

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.

Page 15

**Myositis UK - Charity Registration Number
327791**

**Notes to the Accounts for the year ended 31st
March 2022**

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	2022	2021
Salaries (including ER Costs)	11,917	13,084

No employee received remuneration in excess of £60,000

Average number of employees	1
Administration/Development	1

**Myositis UK - Charity Registration Number
327791**

**Notes to the Accounts for the year ended 31st
March 2022**

4. Analysis of Cost of Raising Funds

	2022 £	2021 £
Fundraising Activities		
London Marathon	1,980	1,980
Miscellaneous	687	681
	<u>2,667</u>	<u>2,661</u>
Total Raising Funds Activities Costs	£ <u>2,667</u>	<u>2,661</u>

5. Analysis of Cost of Charitable Activity

	2022 £	2021 £
Research Costs	-	129,813
Myositis UK Conference	-	-
Office Salary/Tax	11,917	13,084
Printing & Stationary	955	3,858
Postage	1,231	1,664
Telephone & Internet	820	884
	-	
Memberships/Subscriptions	-	163
Website	-	-
Office Equipment/Costs	794	251
Bank Charges	170	103
Miscellaneous Expenses	203	89
	<u>16,090</u>	<u>149,909</u>
Total Payments for Charitable Activity	<u>16,090</u>	<u>149,909</u>
Total Resources Expended	£ <u>18,757</u>	<u>152,570</u>

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

6. Statement of Financial Activities - Analysis of Income

a Restricted	Total	Unrestricted	Restricted	Total	Unrestricted		
		Funds 2021	Funds	2022	Funds		
Grants/Legacies 271,758		-	269,758	269,758	2,000	269,758	
Other Donations/ Fundraising Activities		84,694	-	84,694	71,726	-	71,726
		£ 84,694	269,758	354,452	73,726	269,758	
343,484							

b Other Income Resources

Sundry Income 3,755		483	-	483	3,755	-
		£ 85,177	269,758	354,935	77,481	269,758
347,239						

MYOSITIS UK

England & Wales - Charity number 327791

Accounts

Myositis UK

Registered Charity Number: 327791



**Trustees Report and Financial Statements
For the year ended 31st March 2021**

Myositis UK

Trustees Report 2021

Contents:	Page
Reference & Administrative Details	1
Chairs Review	2-3
Trustees Report	4-10
Independent Examiners Report	11
Statement of Financial Activities	12
Balance Sheet	13
Notes to the Accounts	14-18

Myositis UK

Registered Charity - Charity Registration Number 327791

Reference & administrative Information for the year ended 2021

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
Miss Laura Northcote Trustee

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: Jon Catty FCA
Chartered Accountant, Independent Examiner
12, Durham Road
London N2 9DN

Medical Advisory Panel

Professor Hector Chinoy – The University of Manchester
Dr Patrick Gordon – King's College London
Dr Pedro Machado – University College London
Professor Mike Hanna – Queens Square (University College London)
Dr James Lilleker – The University of Manchester
Dr Harsha Gunawardena – The University of Bristol
Professor Lucy Wedderburn – Institute of Child Health (University College London)
Dr Clarissa Pilkington – Institute of Child Health (University College London)

Myositis UK

Registered Charity - Charity Registration Number 327791

For the Year Ended 31st March 2021

Chairman's review

It could easily be said that last year had been a trying and difficult time for everyone and no doubt the majority of you would agree and ask the question "why state the obvious". I could even deliver a further observation that the year had been rubbish particularly with having to cope and worry about the biggest contributor to these opening words, Covid-19. We have all been affected by this disease and it had led to much sadness in some people's lives while others have lived in the fear of contracting it and living in near isolation with mental health issues compounding it.

It affected the charity in many ways and had the effect of being in deep water trying desperately to keep afloat in the hope of drifting and eventually being marooned safely, and living to fight another day would have been considered a bonus. The charity had not been able to function due to all the restrictions about meeting people and congregating for the fear of spreading infection. This had meant our fundraising ability had been curtailed and the London Marathon event did not take place in the usual manner. The Christmas card sales were down because people couldn't meet to sell them. Likewise, the Christmas charity draw for similar reasons could not take place. The previously successful charity regional meet ups had to cease. The charity book stall had to close and alas has now closed permanently. Our mascot, talisman and seasoned traveller, Teddy-Bo, had been grounded and in hibernation. The biggest disappointment being our Annual General Meeting and Conference being cancelled. Added to the woes the scientific community involved with medical research into myositis had to ease up on their projects to help in the bigger picture of fighting Covid-19.

However, grim as all this may appear this is not the full story. People had been fund raising for the charity, people had been making donations, several anonymously, knowing that we most probably needed help. People had been able to keep in touch through social media by means of the charity forums and pages. The wheels had not fallen off the wagon and Myositis UK still battled on. The issue with myositis is that you have to be careful for the majority living with the illness is vulnerable and need to keep safe. Nevertheless, the charity trustees and friends of the charity continued to play their role knowing we had to push on and get back into top gear. Myositis has no definitive cure but that is because we do not have the funds to discover a cure and it is this reason why the drive and ambition has not been diminished. Just look at what has been achieved in such a short length of time in developing a Covid-19 vaccine. Focus, money, scientific skill and dedication made this possible.

We still had stock of Christmas cards so no new cards were ordered. These were offered for sale at a reduced price.

Myositis UK

Registered Charity - Charity Registration Number 327791

For the Year Ended 31st March 2021

I would like to thank all who raised funds for the charity whether they are members, family, friends or our medical teams. To read and follow these wonderful people in their efforts has been amazing and very heartening. These events and projects have been well reported by the charity and deservedly published in our Charity News magazine and on our relevant web pages. I am particularly grateful to members, family and friends who have donated in memory of loved ones and to those who donated money in celebrating a special family occasion.

My appreciation is offered to the medical teams and their support staff for their tireless energy in helping our members with these miserable conditions, especially during these difficult times.

All charities need committed and dedicated people to make the charity realise its aims and ambition. Our trustees have worked very hard in what can appear to be a thankless task. Treasurer, Jo Goode, is quite remarkable in all her efforts associated with the charity. Auditor, Bridget Kalloushi, has given considerable in overseeing our accounts. The charity's association with Simon Chadwick, who produces our news magazine, is very much appreciated.

When writing last year's report including details of Covid 19 and its effects on the charity who would ever have thought that it would have made such a devastating effect on the world. The development of the vaccines in such a short time was absolutely amazing and proves what fantastic scientists we have in this country and around the world. Hopefully as the vaccine role out has begun, we will in the future be able to hold our meetings in person once again.

Just before the end of this financial year in late March 2021 Myositis UK received a donation of £269,772.71. Myositis UK were the main benefactor in a will. The lady concerned was not a member but her husband who had died before her had suffered from Inclusion Body Myositis. There are restrictions on this money in that it is to be used in the research of Inclusion Body Myositis. In the coming months we will be holding meeting with the relevant researchers and doctors to see how we can best spend this fantastic donation.

I wish you all to keep safe and well.

Les Oakley MBE

Chairman

LC Oakley

26th June 2022

Myositis UK - Charity Registration Number 327791

Trustees Annual Report for the year ended 31st March 2021

The trustees of Myositis UK present their report & financial statement year ended 21st March 2021

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

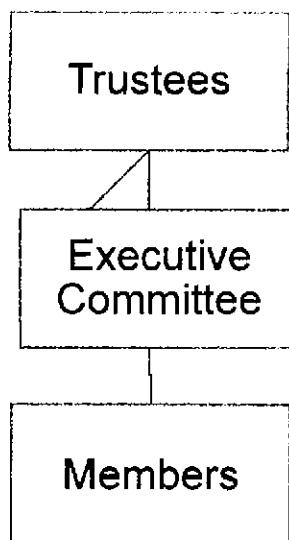
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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 2021**

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

Registered Charity - 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 2020/2021

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 held two webinars on COVID for members with doctors and a physiotherapist. These were very interesting sessions and well received by those who attended on line. The webinars doctors & physio presentations were posted on the charity website, along with resources and covid & Myositis frequently asked questions.

We continue to offer our website & community forum.

Although in a pandemic and with events cancelled members have still been able to take part in fundraising. One of the events was the 2.6 challenge which some members took part in including our Chairman, Les Oakley.

Members continued & took on challenges to fund raise for Myositis UK, Helen Kurtz continued "Helen's Fibre 4 Fibres Fundraiser" throughout the pandemic. Jackie's "Load of Rubbish" fundraiser collected 100 bags of rubbish despite a recent diagnosis of Anti-Synthetase Syndrome and said "I have discovered how therapeutic litter picking is during lock down. It is like a meditation, it's good for the environment and gives my daily exercise a sense of purpose."

The London Marathon Gold Bond purchased by the charity allows us 5 places each year for 5 years; unfortunately, the London Marathon was cancelled this year, but a virtual marathon was organised & one of our runners took part. Runners have their places carried over to next year.

This year we were unable to hold the Christmas Draw, but were able to sell Christmas Cards.

During 2020 – 2021 our bear, "Teddy-Bo", has not been on any travels, so no new photographs have been taken, but hopefully he will continue travelling in the future to help raise awareness of the charity and Myositis.

Due to the Covid 19 pandemic and restrictions on holding meetings the AGM/Conference, which was due to be held in June 2020, was cancelled. The AGM was arranged via Zoom on Sunday 28th March 2021, as not enough members registered to attend to form a quorum it was unfortunately cancelled. The AGM finally took place on Sunday 26th June 2022 via Zoom.

Due to the Covid 19 pandemic Trustees attended no meetings

Myositis UK

Registered Charity - Charity Registration Number 327791

Financial Review – 2020-2021

In the year 2020-2021 total income was £347,239 of which £77,481 was unrestricted £269,758 restricted in comparison in the year 2019-20 income was £68,499 of which £68,499 was unrestricted, there was no restricted income.

Expenditure in 2020-21 total was £152,590 of which £152,570 was unrestricted there was no restricted expenditure in comparison in the year 2019-20 expenditure was £63,671 of which £63,671 was unrestricted, there was no restricted expenditure.

The detailed figures are included in the financial statements. At the year end the charity incurred a deficit of £75,089. A surplus of was £262,990 brought forward for the year 2019-20 leaving an unrestricted surplus to carry forward of £193,901. The restricted funds held at 31st March 2021 are £269,758.

The funds held at 31st March 2021

Unrestricted Fund	193,901
Restricted Funds	<u>269,758</u>
Total Funds 31 st March 2021	£ <u>463,659</u>

Fundraising Activities – 2020-2021

Fundraising activities have been curtailed due to Covid-19, the London Marathon was cancelled, the charity book stall had to close. Supporters/members continued to fund raise for the charity, making donations & holding events. At the end of the financial year the charity received a legacy of £269,772 with restrictions on the gift that it is to be used in research of Inclusion Body Myositis.

Myositis UK

Registered Charity - Charity Registration Number 327791

For the Year Ended 31st March 2021

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 2021/2022:

The Covid 19 pandemic will have an effect on what will be possible in the coming year but we would hope to:

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

- o Continue with our main fund-raising activities – including the selling of Christmas cards for 2021
- o Continue to maintain a good relationship with the medical profession
- o Continue to support our members
- o Continue to fund research

Grants paid in the year ended 31st March 2021

Manchester University, Dr James Lilleker to fund salary (& overheads) of a clinical Fellow to work on the Myositis Guidelines project for 6 months, paid December 2020	25,000
--	--------

Manchester Myositis Research Group, to support the ongoing research programme in Myositis, paid January 2021. This funding will be used to support the backbone of the MMRG, enabling us to meet its ongoing costs associated with running a busy research laboratory. This short-term bridging funding for staff will ensure the continuation to process and analyse samples collected through the UK Myositis Network (UKMYONET) and the MYOPROSP study, as well as supporting the work of other MMRG researchers.	31,982
---	--------

UMCN Radbound 2019 GCOM Speed Funding Research Award – 15,000 euro paid March 2021	<u>13,031</u> £ 70,013
--	---------------------------

Myositis UK

Registered Charity - Charity Registration Number 327791

For the Year Ended 31st March 2021

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).	12,000
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).	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).	30,000
	£ <u>59,800</u>

Myositis UK

Registered Charity - Charity Registration Number 327791

For the Year Ended 31st March 2021

Reserves

The charity's unrestricted reserves are: £193,901

The Charity's restricted fund £269,758

Total funds held at 31st March 2021 £463,659

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 2021 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)

LC Oakley

Signature:

Full Name: Mr Leslie Charles Oakley, MBE

Position: Chairman Date: 26th June 2022

Myositis UK

Registered Charity - Charity Registration Number 327791

For the Year Ended 31st March 2021

Independent Examiners Report

I report on the financial statements for the year ended 31st March 2021, 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 (the 2011 Act) and that an independent examination is needed. I am qualified to undertake the examination by being a qualified member of the Institute of Chartered Accountants in England and Wales.

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 report

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

The charity's gross income exceeded £250,000 and the charity is therefore required to have an independent examination.

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.

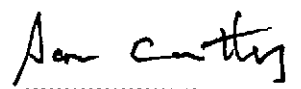
I have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Jon Catty FCA

Independent Financial Examiner

12, Durham Road, London N2 (DN

26th June 2022



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MYOSITIS UK

REGISTERED CHARITY - CHARITY REGISTRATION NUMBER 327791

Statement of Financial Activities for the year ended 31st March 2021

	Note	General Fund £	Restricted Funds £	2021 Total £	Unrestricted Funds £	Restricted Funds £	2020 Total £
INCOME AND ENDOWMENT FORM							
Donations, Grants/Legacies		2,000	269,758	271,758	21,384		21,384
Fund Raising Activities		71,726	-	71,726	45,019		45,019
Other Income Resources		3,755	-	3,755	2,096		2,096
TOTAL INCOMING RESOURCES	6	<u>77,481</u>	<u>269,758</u>	<u>347,239</u>	<u>68,499</u>	<u>0</u>	<u>68,499</u>
EXPENDITURE ON							
Fund Raising Activities		2,661	-	2,661	3,458		3,458
Charitable Activities		149,909	-	149,909	60,213		60,213
TOTAL RESOURCES EXPENDED	5	<u>152,570</u>	<u>269,758</u>	<u>152,570</u>	<u>63,671</u>	<u>0</u>	<u>63,671</u>
NET INCOME/ (EXPENDITURE)		(75,089)	269,758	194,669	4,738		4,738
Before Transfer							
NET MOVEMENT IN FUNDS		<u>(75,089)</u>	<u>269,758</u>	<u>194,669</u>	<u>4,738</u>	<u>0</u>	<u>4,738</u>
Total Funds brought forward at 31st March 2020		268,990	-	268,990	264,252		264,252
TOTAL FUNDS carried forward at 31st March 2021 (Page 7)		<u>193,901</u>	<u>269,758</u>	<u>463,659</u>	<u>268,990</u>	<u>0</u>	<u>268,990</u>

The notes form part of these accounts

Myositis UK

Registered Charity – Charity Registration Number 327791

Balance Sheet as at 31st March 2021

	Notes	2021	2020
		£	£
FIXED ASSETS			
Tangible Assets		-	-
CURRENT ASSETS			
Debtors		-	-
Cash at Bank & on Deposit		<u>524,238</u>	<u>268,990</u>
CURRENT LIABILITIES			
Income in Advance		779	-
Accruals (page 9)		59,800	-
Amounts falling due within one year		<u> </u>	<u> </u>
NET CURRENT ASSETS		<u>463,659</u>	<u>268,990</u>
FUNDS			
General Fund		193,901	268,990
Restricted Funds (note 6)		<u>269,758</u>	<u> </u>
TOTAL FUNDS		<u>463,659</u>	<u>268,990</u>

The notes on form part of these accounts

The accounts were approved by the Board of Trustees on 26th June 2022 and signed on its behalf by:

L C Oakley

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Mr Leslie Charles Oakley MBE

Date 26th June 2022

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2021

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 102) (effective 1st January 2019) - (Charities SORP FRS 102). The charity meets the definition of a public benefit entity under FRS 102. 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 102) 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.

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2021

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.

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2021

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	2021	2020
Salaries (including ER Costs)	13,084	10,579

No employee received remuneration in excess of £60,000

Average number of employees 1

Administration/Development 1

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2021

4. Analysis of Cost of Raising Funds

	2021	2020
	£	£
Fundraising Activities		
London Marathon	1,980	1,980
Miscellaneous	681	-
Christmas Draw	-	1,568
Total Raising Funds Activities Costs	£ 2,661	3,548

5. Analysis of Cost of Charitable Activity

	2021	2020
	£	£
Research Costs	129,813	28,000
Myositis UK Conference	-	12,170
Office Salary/Tax	13,084	10,579
	-	-
Printing & Stationary	3,858	2,814
Postage	1,664	2,291
Telephone & Internet	884	650
	-	150
Memberships/Subscriptions	163	155
Website	-	2,112
Office Equipment/Costs	251	885
Bank Charges	103	158
Miscellaneous Expenses	89	249
Total Payments for Charitable Activity	149,909	60,213
Total Resources Expended	£ 152,570	

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

Myositis UK - Charity Registration Number 327791

Notes to the Accounts for the year ended 31st March 2021

6. Statement of Financial Activities – Analysis of Income

a	Unrestricted Funds	Restricted Funds	Total 2021	Unrestricted Funds	Total 2020
Donations, Grants/Legacies	2,000	269,758	271,758	21,384	21,384
Other Donations/Fundraising Activities	71,726	-	71,726	45,019	45,019
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
£	73,726	269,758	343,484	66,403	66,403

b Other Income Resources

Sundry Income	3,755	-	3,755	2,096	2,096
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£	77,421	269,758	347,239	68,499	68,499
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