

Myositis UK

Registered Charity Number: 327791



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

Myositis UK

Trustees Report 2021

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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

L C 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

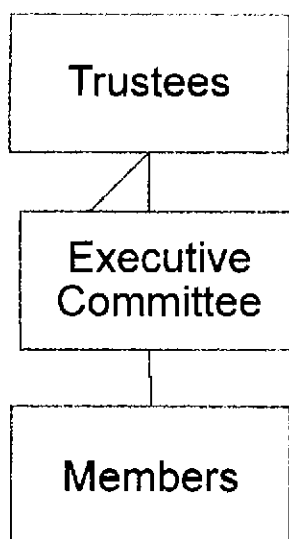
Decisions are reached by consensus or, when necessary, by majority vote among the (at minimum) two voting members attending.

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

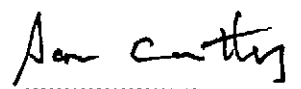
I have come across no matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

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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