



POLYMYALGIA RHEUMATICA and GIANT CELL ARTERITIS SCOTLAND

(PMR-GCA SCOTLAND)

Scottish Charity Number: SC037780

Report and Accounts

for the year ended 31 December 2020

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OFFICERS including Management Committee	Chair and Principal	Mr Richard Cuthbert
	Registered Address	7 Hamilton Place PERTH PH1 1BB
	Secretary	Mr Michael Benneworth
	Treasurer	Mr Harvie Findlay
	Committee	Mrs Lorna Neill Mr William Hughes
	Non-voting members	Mr David Carrott Mrs Anne Hughes

Mrs Lorna Neill and Mr Harvie Findlay retire by rotation and are available for re-election as trustees.

GOVERNANCE The Organisation was formed as an unincorporated association on 24 February 2006 and was granted Charitable Status with effect from 6 February 2007.
These Accounts cover the year ended 31 December 2020.

**CONSTITUTIONAL
CHANGES** There have been no constitutional changes.

**ORGANISATIONAL
STRUCTURE** The Organisation is administered by the Officers and Management Committee, who are the charity trustees. At each Annual General Meeting one third in number of the members of the Management Committee shall retire by rotation but may be re-elected or re-appointed. Any interim vacancy arising during the year shall be filled after consultation with the members. Any Officer so appointed during the year shall retire at the next Annual General Meeting following his/her appointment but may be re-elected or re-appointed.

**RECRUITMENT OF
MEMBERS OF
MANAGEMENT
COMMITTEE** Throughout the year, the charity was continuously served by a Chair, Secretary, Treasurer and two additional trustees. The charity is grateful to members who attended committee meetings, on an advisory, non-voting basis during the year.

**CHARITABLE
PURPOSES** The objective of the Organisation is to provide support for all affected either directly or indirectly by Polymyalgia Rheumatica (PMR) and Giant Cell Arteritis (GCA). This is done through regular meetings, the telephone helpline, by email and via the website and Facebook page. The Organisation also aims to raise the profile and awareness of these conditions with both the general public and Health Professionals and to encourage research.

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The Chair, and/or an assigned depute, attended or took part in the following

16/01/20	PMR research teleconference
21/01/20	OMERACT PMR teleconference
10/02/20	OMERACT PMR teleconference
24/02/20	Patient input to research at Chapel Allerton Hospital, Leeds
25/02/20	Trustees meeting, Dundee
11/03/20	OMERACT PMR teleconference
20/03/20	AGM by email
14/04/20	Teleconference on Adrenal Insufficiency
26/05/20	Trustees meeting by email
01/06/20	Alliance AGM online
04/06/20	EULAR meeting online
17/06/20	Webinar – Prof B Dasgupta
22/06/20	Webinar – Dr S Muller
30/06/20	OMERACT teleconference on Flare
08/07/20	CPG meeting online
21/07/20	Joint meeting of Highland, Aberdeen and Dundee support groups online
29/07/20	OMERACT teleconference on Shared Decision Making
04/08/20	Webinar – Dr S Mackie
11/08/20	Joint meeting of Glasgow and Edinburgh support groups online
13/08/20	CPG meeting online
25/08/20	Trustees meeting online
05/09/20	PMRGCAuk AGM online
16/09/20	Joint meeting of all support groups online
23/09/20	CPG meeting online
08/10/20	PMR research teleconference

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The Chair, and/or an assigned depute, attended or took part in the following

14/10/20	Scottish Systemic Vasculitis Network telephone meeting
16/10/20	Joint meeting of all support groups online
20/10/20	OMERACT online workshop on glucocorticoids
27/10/20	Alliance meeting online
03/11/20	Research teleconference on Physical Therapies for PMR/GCA
04/11/20	CPG meeting online
12/11/20	OMERACT teleconference on Contextual Factors
16/11/20	Joint meeting of all support groups online
18/11/20	OMERACT teleconference on RCTs
23/11/20	EULAR research teleconference
24/11/20	Trustees meeting online
25/11/20	Prof B Dasgupta webinar on Diagnosis of PMR
30/11/20	EULAR research teleconference
02/12/20	EULAR research teleconference
04/12/20	EULAR PMR/GCA workgroup virtual meeting
08/12/20	OMERACT teleconference for PMR Group
16/12/20	Prof B Dasgupta webinar on Management of PMR
17/12/20	Scottish Systemic Vasculitis Network meeting online
Throughout	Members act as volunteer patients who help in the training of doctors in St. Andrews Medical School and Ninewells Hospital, Dundee.

Involvement with research

PMR-GCA Scotland personnel are involved in many areas of research and development, both national and international e.g. Patient Research Partner in OMERACT Working Groups on PMR, Stiffness, and Glucocorticoid-related Adverse Events and member of the BSR GCA Guidelines Group.

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Acronyms and abbreviations

CPG	Scottish Parliament's Cross Party Group on Musculo-Skeletal Conditions
OMERACT	International collaboration on Outcome Measures in Rheumatology
BSR	British Society for Rheumatology
EULAR	European League Against Rheumatism
RCT	Randomised Controlled Trial

OTHER ORGANISATIONS

We are members of the following organisations:

PMRGCauk: Although no longer formally affiliated, we attempt to work closely together but remain distinctly separate organisations. PMR-GCA Scotland continues to have a dedicated page in the tri-annual newsletter which is mailed or emailed to all our supporters.

The Health and Social Care Alliance Scotland (The Alliance): The ALLIANCE now brings together an astonishing 1500+ organisations and over 370 individual members to ensure the voice of people and unpaid carers, and the expertise of the voluntary sector, are influential in shaping policy and practice. PMR-GCA Scotland contributes to Scottish Government consultations where it feels that it is able to offer insight. Past Chair, Bea Nicholson, maintains a watching brief over conferences, consultations etc. and, where necessary, speaks on our behalf.

Holyrood Cross Party Group (CPG): PMR-GCA Scotland retains its membership of the Arthritis and Musculoskeletal Conditions group and attends regularly. The meetings are held in the Scottish Parliament building, are chaired by a Scottish Member of Parliament and look at areas of interest to the member organisations with the hope of bringing these to the attention of MSPs where action is needed.

The Helplines Association: Membership of this association, at "Our Community" level allows the charity to benefit from best practice experience and provides training courses for our volunteers.

Scottish Council for Voluntary Organisations (SCVO): SCVO works in partnership with the voluntary sector to advance our shared values and interests. It has over 1500 members who range from individuals and grassroots groups, to Scotland-wide organisations and intermediary bodies. Through lobbying and campaigning SCVO works to advance the interests of our members and the people and communities that they support. PMR-GCA Scotland is classified as a grassroots group and does not pay a membership fee but is able to benefit from their advice and literature.

Scottish Systemic Vasculitis Network (SSVN): This is a National Managed Clinical Network for Scotland which will provide expertise throughout the country for all systemic vasculitis illnesses, including GCA and Large Vessel Vasculitis (LVV) which are the commonest types in older people.

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OVERVIEW

In last year's report 2019 was described as a year of consolidation. The importance of that consolidation has been highlighted in the difficult circumstances which have affected much of our activity in 2020. With our stronger operating base we have been able to function and deliver support to members and patients across the country whilst preserving safety at all times.

The most obvious impact of the pandemic was to cancel the regular meetings of our support groups. This is our most visible activity and is enjoyed by many members for the medical and social benefits that flow from it. We are pleased to report that this void was quickly filled due to the determination of David Carrott. He arranged for meetings of the Aberdeen and Highland support groups to be held on Zoom, and following on from that success we were able to involve the other support groups in online meetings. From this important beginning we introduced a series of nationwide online meetings which took the form of a topical presentation followed by general questions and discussion. Our thanks go to David for his drive during the initial setup, allied to his technical knowhow which helped to keep it going. We also thank Michael Benneworth for his administrative and technical input. We hope to maintain similar online contact sessions until we are able to resume our traditional meetings. Many members have difficulty in attending support group meetings due to health, distance, timings and work commitments so we will investigate the case for keeping some online activity in the future if there is a demand for it.

The other main objective of the charity is to promote research activities into PMR and GCA. During the year we awarded a grant to support research work being undertaken at Edinburgh University into Large Vessel Vasculitis. This work is looking at new imaging techniques which can give a more accurate assessment of disease activity compared to current blood tests where the results can be inconclusive. More accurate information should allow more targeted and appropriate treatments – no more steroid being taken than necessary, and indeed none if there is no requirement. We have also given support to funding applications for a project to investigate relapses in GCA patients. It is hoped that a better understanding of the factors which lead to a relapse will help to determine which patients need the highest doses of steroid and which might be able to use lower doses of these powerful drugs.

Our AGM in March had to be converted at short notice to an email operation. Whilst this was a success from an administrative point of view it deprived us of the opportunity to show in person our appreciation of Lorna Neill who stood down from the position of Chair. Lorna has been a tireless worker for the charity over the last ten years being heavily involved with the Dundee support group and being Chair of the charity since 2016. Behind the scenes, however, she does even more work with involvements in various groups and research bodies, both national and international. An understanding of the schedule of activities on page 3 is enhanced when one realises that Lorna was at nearly all of them. As if that was not enough, Lorna is also a volunteer on the Helpline. Thank you, Lorna, for all that you have done on behalf of the charity and we are delighted that you continue to be a Trustee and intend to maintain many of your external connections which greatly benefit the charity.

LOCAL SUPPORT GROUPS

We have five groups operating which, in normal circumstances, meet regularly, monthly or bimonthly, in Aberdeen, Dundee, Glasgow, Edinburgh, and Inverness (Highland). Attendance at meetings averages around ten, although many more (about a third of our membership) are listed as group members and a special event or speaker can bring in an audience nearer twenty. Socialising over tea and coffee or the occasional meal, along with sharing experience and mutual support, form the content of the meetings. Speakers are invited from time to time on topics of interest which can range from patient-centred issues to information on medical research and advances.

Any member may start up a group if they would like to do so. The first step is to find a venue, which may be a local hall or even a cafe, a few members who wish to meet up, then to act as contact person. The charity has agreed to

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support new groups while they find their feet, and we can provide help from someone who has done it before, or financial assistance should it be needed. Such assistance could include room hire, speaker expenses, publicity etc., although all groups are encouraged to become self-sufficient when possible. Contact the Secretary by email or by phoning the Helpline and leaving a message if you would like to volunteer in this way.

Fuller and current information about all the groups is available on the Website at www.pmgcascotland.com/home

HELPLINE

The Helpline is one of our most important activities and is operated by a committed team of volunteers. They are the first point of contact for many newly diagnosed patients and the support and information given out is very important. Most patients are bewildered by a diagnosis of PMR or GCA because they have never heard of the conditions before. It is a great comfort to many when they make contact with the Helpline and receive practical information to assist in those early days, and indeed throughout the later stages as fresh challenges arise.

The charity has five volunteers located across Scotland who answer calls to the Helpline. This means that each volunteer will work for only one week in five, during which they both give out information about the charity and act as a friendly and understanding listener as necessary. All have or have had PMR and/or GCA. Coordination and management of the system through Windsor Telecom and organisation of the volunteer rota continue to be handled by Helen Faccenda. All volunteers are encouraged to attend appropriate courses, run by the Helplines Association of which we are a member, and expenses incurred are fully funded by the charity.

If you are interested in helping with this activity then please contact us through the website or by calling the Helpline number.

Calls average about 2 or 3 per week although the number has been a bit lower in the last 12 months and some enquiries are now made via our website. Calls can be routine enquiries taking a few minutes or they can last for up to an hour – all appreciate our help whether it be a new caller or a returnee. We operate between 9am and 9pm but if no one is available to take a call, a recorded message asks the caller to leave their name and phone number and the volunteer will phone back as soon as possible. Our policy is not to phone back to a missed call unless this permission is given.

FACEBOOK and TWITTER

Find us at www.facebook.com/pmgcascotland/ and @pmrgcascotland. We are keen to hear from members who can help us to manage these accounts. If you are interested in assisting here please contact us through the website.

INFORMATION PACKS, NEWSLETTERS and MEMBERSHIP

There were two changes in the contents of the packs in 2020. The replacement of the Royal Osteoporosis Society (ROS) postcard with their “Contact us” leaflet. We also replaced the old GCA flowchart with a summary of the 2020 British Society for Rheumatology (BSR) guideline on diagnosis and treatment of giant cell arteritis: highlights for patients.

We mailed out 24 packs in 2020 down from 38 in 2019. The 5 year average is 44. Requests for packs come from Helpline, Web and other sources such as friends. Feedback from recipients remains encouraging. Requests for packs was greatly reduced during lockdown.

The packs contain a variety of information from various sources. There are 2 different packs – a standard pack which most people have and a medical pack for those who want more detail about the conditions. The standard pack includes a summary of the medical pack. The charity still aims to provide documentation free of charge and continues to ensure that the enclosures are customised to the needs of the individual caller wherever possible.

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Newsletters are mailed out 3 times a year and over 88% are sent out within Scotland.

We currently have 286 members (287 in 2019), of these 57% (50% in 2019) are in contact with us each year. Over 77% (75% in 2019) are in contact over a two year period.

We tend to lose about 10% to 15% of our membership each year either because of death, recovery or getting their condition under control. This year it was 11% but it was almost matched by new members. Therefore, in January 2020 we had 287 members and we now have 286.

WEBSITE

The website continues to be a useful source of information for many people, both medical and non-medical, providing also the point of contact for many new members. This year has seen a settling down of the revamp of the website (and change in name). Our website is www.pmrgcascotland.com. During the year we made a change to automatically transfer visitors from the old site to the new website. With having 2 websites running together it is difficult to produce accurate statistics (we can't just add together unique visitors from both sites). Our estimate is that the number of unique visitors for the year is similar to last year at over 15,000. For the new website we have 2 visits per visitor and 4 pages viewed per visit. This tends to indicate that people are looking for a specific item rather than general browsing. Our old website will be active until 19th January 2023 but as there is no access it will only be used for rerouting and so can be excluded from future statistics. Although most visitors are UK based, we do get contacts from elsewhere in the world and endeavour to help where possible.

FINANCIAL REVIEW

The Receipts and Payments Account shows a deficit for the year of £558, all of which is in respect of Unrestricted Funds. There is no movement in Restricted Funds during the year.

During the year, we received donations of £4,334, including donations of £3,000 from charitable trusts. The support of charitable trusts is an important part of our funding and we are extremely grateful to those trusts which supported us in 2020. Not surprisingly, in this year of the coronavirus pandemic, donations from individuals, at £1,334, were lower than last year's figure of £3,300 but we hope this will recover in future years. Including gift aid of £986, our total income was £5,320 compared to £6,884 last year.

So far as costs are concerned, our overall costs, at £5,878, are well down on last year's figure of £9,641. This is principally due to the fact our annual conference, normally our most costly single event, had to be cancelled due to the pandemic. In addition, there were savings in some other costs where activities were held remotely rather than in person and these savings were welcome given the reduction in our income as noted above. During the year we made a research grant of £1,500 (2019 - £2,500).

The financial picture for both income and costs was affected throughout the year as a result of the current pandemic but we have managed to complete the year with just a relatively modest deficit and at the year end the organisation had total Restricted and Unrestricted Funds of £22,903, placing the charity in a satisfactory financial position to continue its work in the coming years.

Once again, the trustees are extremely grateful to all those individuals and trusts who have given financial support to the charity in 2020.

Richard Cuthbert, Chair

1 February 2021

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Independent examiner's report to PMR-GCA Scotland

I report on the accounts of the charity for the year ended 31 December 2020 which are set out on pages 10 to 12.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. The charity's trustees consider that the audit requirement of Regulation 10(1) (d) of the 2006 Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under section 44(1) (c) of the Act and to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination is carried out in accordance with Regulation 11 of the 2006 Accounts Regulations. 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 seeks explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

In the course of my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that in any material respect the requirements:
 - to keep accounting records in accordance with Section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and
 - to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations have not been met, or
1. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Sheena Gibson FCCA
James Hair & Co
59 Bonnygate
Cupar
KY15 4BY

1 February 2021

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RECEIPTS AND PAYMENTS ACCOUNT

FOR THE YEAR ENDED

31 DECEMBER 2020

2019 £	RECEIPTS	2020 £	2020 £	2020 £
Total		Unrestricted	Restricted	Total
6,300	Donations	4,334	-	4,334
584	Gift Aid repaid	986	-	986
-	Bank Interest	-	-	-
-	Miscellaneous	-	-	-
6,884	Total receipts	5,320	-	5,320
	PAYMENTS			
763	Advertising/Information	732	-	732
1,006	Postage	1,077	-	1,077
239	Stationery	333	-	333
402	Delegate Expenses	-	-	-
50	Donations for Hall	-	-	-
-	Donations/Presentations	-	-	-
1,952	AGM and Annual Conference	92	-	92
369	Support Groups	35	-	35
347	Insurance	347	-	347
248	Helpline Costs	254	-	254
1,136	Volunteer Expenses	170	-	170
142	Computer/website	839	-	839
151	Subscriptions	151	-	151
2,500	Research Grants Awarded	1,500	-	1,500
9,305	Total payments for charitable activities	5,530	-	5,530
336	Examiner's fee	348	-	348
9,641	Total payments	5,878	-	5,878
(2,757)	Surplus/(deficit) for period	(558)	-	(558)

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STATEMENT OF BALANCES AS AT 31 DECEMBER 2020

2019 £		2020 £
	<u>Bank and Cash Balances</u>	
26,218	At beginning of period	23,461
(2,757)	Surplus/(deficit) for period	(558)
23,461	At end of period	22,903
	<u>Reserves</u>	
22,664	Unrestricted reserves	22,106
797	Restricted reserves	797
23,461	Total Reserves	22,903

	<u>Assets</u>	
-	Computer and website	-
	<u>Liabilities</u>	
345	Independent Examiner's fee	360
	<u>Debtors</u>	
987	Gift Aid Repayment to 31 December 2020	237

Approved by the Management Committee and signed on their behalf on 1 February 2021

Richard Cuthbert, Chair

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NOTES TO THE ACCOUNTS

FOR THE YEAR TO 31 DECEMBER 2020

1. No member of the Management Committee received remuneration.
2. Mrs Lorna Neill received reimbursement of £29 (2019 - £97) in respect of costs incurred by her during the year. Of this £29 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland.

Mr J Michael Benneworth received reimbursement of £2,059 (2019 - £1,689) in respect of costs incurred by him during the year. Of these £2,047 related to operational costs and £12 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland.

Mr Harvie Findlay received reimbursement of £nil (2019 - £279) in respect of costs incurred by him during the year.

Mr Richard Cuthbert received reimbursement of £31 (2019 - £36) in respect of costs incurred by him during the year. Of this £31 related to travel costs incurred carrying out his duties in connection with PMR-GCA Scotland.

Mr William Hughes received reimbursement of £98 (2019 - £247) in respect of costs incurred by him during the year. Of this £98 related to travel costs incurred carrying out his duties in connection with PMR-GCA Scotland.