



POLYMYALGIA RHEUMATICA and GIANT CELL ARTERITIS SCOTLAND

(PMR-GCA SCOTLAND)

Scottish Charity Number: SC037780

Report and Accounts

for the year ended 31 December 2019

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OFFICERS including Management Committee	Chair and Principal	Mrs Lorna Neill
	Registered Address	7 Hamilton Place PERTH PH1 1BB
	Secretary	Mr Michael Benneworth
	Treasurer	Mr Harvie Findlay
	Committee	Mr Richard Cuthbert (appointed 26 November 2019) Mr William Hughes (appointed 26 November 2019)
	In attendance as non-voting members	Mr David Brockett, Mr David Carrott, Mrs Anne Hughes

Mr Michael Benneworth retires by rotation and is available for re-appointment.

Mr Richard Cuthbert and Mr William Hughes were appointed during the year and are available for re-appointment 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 2019.

**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, and Treasurer and two additional trustees were appointed during the year. 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

04/02/19	PMR research teleconference
05/02/19	OMERACT PMR teleconference
12/02/19	Visit to Wishaw Hospital, Lanarkshire
21/02/19	Patient input to research at Chapel Allerton Hospital, Leeds
26/02/19	Trustees meeting, Dundee
01/03/19	PMR research webinar
06/03/19	HIS/SMC webinar on ultra-orphan medicines
08/03/19	Talk to Montrose YMCA Ladybirds group.
12/03/19	OMERACT PMR teleconference
13/03/19	CPG Holyrood
28/03/19	Meeting with representative of Roche Products Ltd, Edinburgh
25/04/19	OMERACT PMR teleconference
15/05/19	CPG Garden Lobby Event Holyrood
20/05/19	Alliance AGM
05/06/19	PMR research teleconference
14/06/19	Inaugural meeting of Aberdeen group.
24/06/19	Trustees meeting, Dundee
25/06/19	PMR research teleconference
27/06/19	OMERACT PMR teleconference
02/07/19	PMR research teleconference
19/07/19	PMR research teleconference
27/08/19	Trustees meeting, Dundee
07/09/19	PMRGCAuk AGM, London
10/09/19	OMERACT PMR webinar
11/09/19	CPG Holyrood

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

12/09/19	SMC focus groups, Glasgow
08/10/19	OMERACT PMR teleconference
09/10/19	Roche GCA meeting, Edinburgh plus meeting at Roche HQ in Welwyn Garden City
06/11/19	CPG, Holyrood
25/11/19	Scottish Parliament Health and Sport Committee, Perth
26/11/19	Trustees meeting - Dundee
26/11/19	OMERACT PMR teleconference
28/11/19	DVA Extraordinary General Meeting
04/12/19	PMR research teleconference
09/12/19	PMR research teleconference
12/12/19	Scottish Systemic Vasculitis Network launch, Stirling
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.

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
SMC	Scottish Medicines Consortium
PET/MRI	Positron Emission Tomography/Magnetic Resonance Imaging
DVA	Dundee Voluntary Action
HIS	Health Improvement Scotland

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OVERVIEW

2019 has been a year of consolidation.

We have seen the charity's emphasis on improving knowledge, diagnosis and treatment of GCA, which started with the Glasgow seminar organised by past chair Bea Nicholson in September 2016, culminating in many local Health Boards now providing some sort of Fast Track service. The use of ultrasound for diagnosis is increasing and specialist training for this has been the focus of our small grant allocations in the past year. As these changes become established and familiarity with Tocilizumab for GCA increases we hope that avoidable sight loss reduces throughout the country to the level of those areas providing best practice. NHS Scotland's setting up of a Systemic Vasculitis Support Network should guide these improvements and disseminate knowledge to those parts of the country which are without the support of an experienced consultant.

At last year's AGM there was an appeal for more volunteers to join those already taking on the tasks required to enable PMR-GCA Scotland to function. Soon we had a new Helpline volunteer who has brought with her previous expertise in nursing and helplines. This has solved the problem that used to occur when holidays or sickness meant long spells of duty for the remaining volunteers and allows us to maintain a service that provides information and support from 9am till 9pm every day of the year.

In addition, three members have been added to those attending the Trustees Committee as non-voting advisors and it is to be hoped that some will be elected as Trustees to enable the Management Committee to be strengthened.

Finally, our thanks again to David Carrott who, after successfully forming the Highland group, took on the task of helping Aberdeen members set up a Support Group for the North East. We can now say that all our larger cities contain a meeting point for those with PMR/GCA along with their friends and family.

As always, we try our best to ensure that the patient's voice is heard whenever research or treatment is being planned. "No decision about us without us" has been a slogan used within the NHS since 2012 but still must be fought for. The charity's voice on behalf of patients has been heard this year at Holyrood, during collaboration with researchers at home and abroad, in the education of medical students, professional development for GP trainees and consultants and in consultation with Roche Products Ltd. (the makers of Tocilizumab for GCA). Many thanks to those members involved.

LOCAL SUPPORT GROUPS

We now have five groups meeting regularly, monthly or bimonthly, in Aberdeen, Dundee, Glasgow, Edinburgh, and Inverness (Highland). Attendance at any meeting 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. Some come regularly, some drop in from time to time and we have the occasional summer visitor from PMRGCAuk, on holiday but still looking for understanding company. 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 such as Physiotherapy or Tai Chi, local pharmacists, GPs or rheumatologists, or from Scottish Health Council representatives on for example Patient Engagement within the NHS.

Any member may start up a group if they would like to do so. All that is involved is to find a venue, which may be a local hall or even a cafe, and a few members who wish to meet up, then to act as contact person. The charity has agreed to support new groups while they find their feet, providing help from someone who has done it before, or financially should it be needed. Such expenses could include room hire, speaker expenses, publicity etc., although

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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.pmrgcascotland.com/home

HELPLINE

The charity now 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. This year our new volunteer, although having previous helpline experience, was able to update her knowledge before starting.

We received 138 calls during 2019 which is down from last year (172). A few lasted nearly an hour, although simple enquiries are dealt with more quickly. Some of these are new callers, some repeat calls. If no one is available to take a call, a 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.

With minor peaks and troughs, the volume of calls averages about 2-3 calls a week, although people are now choosing to email for information using the Website contact. There were about 50 such requests again this year.

FACEBOOK and TWITTER

Find us at www.facebook.com/pmrgcascotland/ and @pmrgcascotland. We are still looking for members who will help manage these accounts.

INFORMATION PACKS, NEWSLETTERS and MEMBERSHIP

There were no changes in the contents of the standard pack in 2019 nor in the contents of the Medical Pack.

We mailed out 38 packs in 2019 down from 56 packs in 2018, 44 in 2017, 60 in 2016 and 39 in 2015. The 5 year average is 47. Requests for Packs come from the HelpLine (15 in 2019, 19 in 2018, 16 in 2017), Web (21 in 2019, 19 in 2018, 12 in 2017) and other sources (2 in 2019, 18 in 2018, 16 in 2017). Feedback from recipients remains encouraging so the packs are a valuable part of the charity's offering

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 and recipients are invited to request this more detailed pack if they wish. The charity still aims to provide documentation free of charge and continues to ensure that the enclosures are customised to each individual caller's needs wherever possible.

Copies of the newsletters are mailed out 3 times a year to Members, Supporters and Other contacts. Of these over 85% are sent out in Scotland. The furthest one is sent to Kenya.

We currently have 287 members, 50% (43% in 2018 and 2017) are in contact with us each year either by ringing the helpline, coming to the AGM or attending a Group Meeting. Over 75% (71% in 2018, 65% in 2017) are in contact over a two-year period. Members are encouraged to get in touch regularly to ensure that they keep

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receiving mailings. Over a five-year period, there has been over a 40% increase in the members living in Scotland and a 65% reduction in the number living in England.

We tend to lose over 15% of our membership each year either because of death, recovery or getting their condition under control. This year it was lower at 13% but it was almost matched by new members. Therefore, in January 2019 we had 289 members and we now have 287. About a half of our members are associated with one of the 5 local groups.

WEBSITE

The website, in conjunction with the Helpline, continues to be a useful source of information for many people, both medical and non-medical, providing also the point of first contact for many new members. This year has seen a revamp of the website and a change in name. Our website is now www.pmrgcascotland.com. With having 2 websites running at the same time 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 17,500 (we had over 16,000 to the old website) and the activity averages over 15,000 "hits" a month (20,000 in 2018). Although most visitors are UK based, we do get contacts from elsewhere in the world and endeavour to help where possible.

Most visitors go direct to the site using a bookmark from previous visits or from a link in an email. Some arrive from search engines such as Google while a small proportion of visitors are routed from other websites e.g. Facebook, patient.co.uk or PMRGCAuk.

Our annual hosting fee still provides excellent value for money. We intend to run the old website for 2 years to ensure traffic is rerouted and emails are not lost.

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

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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.

FINANCIAL REVIEW

The Receipts and Payments Account shows a total deficit for the year of £2,757. Of this, there is a deficit on Unrestricted Funds of £1,757 and a deficit on Restricted Funds of £1,000.

During the year, we received unrestricted donations of £4,800, of which £1,500 represented donations from charitable trusts. As in 2018, we did not actively appeal for donations from charitable trusts in 2019 given the level of reserves in hand, but we sincerely hope that we can rely on the support of trusts in the coming years as the requirement arises. We also received a restricted donation of £1,500 and consequently our total income, including gift aid, amounted to £6,884, slightly higher than last year's total income of £6,712.

Our costs continue to be well managed and this year in total, excluding the award of research grants, amounted to £7,141. In 2019, our AGM and annual conference was held in Glasgow at higher cost than is normally the case in Dundee. Costs in general were broadly similar to last year although the cost of travel for our volunteers was higher than normal in 2019. We still believe that overall the costs associated with running the charity are relatively modest in relation to the activities carried out for the benefit of those who are affected directly or indirectly by PMR and/or GCA.

In addition to our operational costs, we made two research grants totalling £2,500 to support research and training in ultrasound diagnosis for GCA.

At the year end the organisation had total Restricted and Unrestricted Funds of £23,461, placing the charity in a healthy 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 2019.

Lorna Neill, Chair

28 January 2020

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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 2019 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
For and on behalf of
MHA Henderson Loggie
The Vision Building
20 Greenmarket
Dundee
DD1 4QB

28 January 2020

MHA Henderson Loggie is a trading name of Henderson Loggie LLP

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RECEIPTS AND PAYMENTS ACCOUNT

FOR THE YEAR ENDED

31 DECEMBER 2019

2018 £	RECEIPTS	2019 £	2019 £	2019 £
Total		Unrestricted	Restricted	Total
6,277	Donations	4,800	1,500	6,300
435	Gift Aid repaid	584	-	584
-	Bank Interest	-	-	-
-	Miscellaneous	-	-	-
6,712	Total receipts	5,384	1,500	6,884
	PAYMENTS			
679	Advertising/Information	763	-	763
1,019	Postage	1,006	-	1,006
448	Stationery	239	-	239
509	Delegate Expenses	402	-	402
50	Donations for Hall	50	-	50
-	Donations/Presentations	-	-	-
1,203	AGM and Annual Conference	1,952	-	1,952
25	Support Groups	369	-	369
327	Insurance	347	-	347
221	Helpline Costs	248	-	248
730	Volunteer Expenses	1,136	-	1,136
147	Computer/website	142	-	142
156	Subscriptions	151	-	151
1,500	Research Grants Awarded	-	2,500	2,500
7,014	Total payments for charitable activities	6,805	2,500	9,305
324	Examiner's fee	336	-	336
7,338	Total payments	7,141	2,500	9,641
(626)	Surplus/(deficit) for period	(1,757)	(1,000)	(2,757)

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STATEMENT OF BALANCES AS AT 31 DECEMBER 2019

2018 £		2019 £
	<u>Bank and Cash Balances</u>	
26,844	At beginning of period	26,218
(626)	Surplus/(deficit) for period	(2,757)
26,218	At end of period	23,461
	<u>Reserves</u>	
24,421	Unrestricted reserves	22,664
1,797	Restricted reserves	797
26,218	Total reserves	23,461

-	<u>Assets</u>	
	Computer and website	-
	<u>Liabilities</u>	
335	Henderson Loggie - Independent Examiner's fee	345
	<u>Debtors</u>	
584	Gift Aid Repayment to 31 December 2019	987

Approved by the Management Committee and signed on their behalf on 28 January 2020

Lorna Neill, Chair

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NOTES TO THE ACCOUNTS

FOR THE YEAR TO 31 DECEMBER 2019

1. No member of the Management Committee received remuneration.
2. Mrs Lorna Neill received reimbursement of £97 (2018 - £1,407) in respect of costs incurred by her during the year. Of this £97 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland.

Mr J Michael Benneworth received reimbursement of £1,689 (2018 - £2,039) in respect of costs incurred by him during the year. Of these £1,616 related to operational costs and £73 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland.

Mr Harvie Findlay received reimbursement of £279 (2018 - £nil) in respect of costs incurred by him during the year. Of this £279 related to operational costs incurred carrying out duties in connection with PMR-GCA Scotland.

Mr Richard Cuthbert received reimbursement of £36 (2018 - £nil) in respect of costs incurred by him following his appointment as a trustee. Of this £36 related to travel costs incurred carrying out his duties in connection with PMR-GCA Scotland.

Mr William Hughes received reimbursement of £247 (2018 - £nil) in respect of costs incurred by him following his appointment as a trustee. Of this £247 related to travel costs incurred carrying out his duties in connection with PMR-GCA Scotland.