



POLYMYALGIA RHEUMATICA and GIANT CELL ARTERITIS SCOTLAND

(PMR-GCA SCOTLAND)

Scottish Charity Number: SC037780

Report and Accounts

for the year ended 31 December 2017

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

OFFICERS including Management Committee	Chair and Principal	Mrs Lorna Neill	Re-appointed	24 th March 2017
	Registered Address	7 Hamilton Place Perth Perthshire PH1 1BB		
	Secretary	Mr Michael Benneworth	Re-appointed	24 th March 2017
	Treasurer	Mr Harvie Findlay		
	Committee	Mrs. Marion Read	Interim appointment	22 nd Aug. 2017
	In attendance as non-voting members	David Brockett David Carrott Brian FitzPatrick		

Mr. Harvie Findlay retires by rotation and is available for re-appointment as treasurer.

Mrs. Marion Read retires but is not available for re-appointment as a trustee.

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 2017.

**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. Additional trustees are still urgently sought. 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.

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

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

21/02/17	Trustees meeting - Dundee
24/02/17	Fife Rheumatologists – Whyteman's Brae Hospital, Kirkcaldy
01/03/17	CPG – Holyrood, Edinburgh.
02/03/17	Talk to University of the Third Age – Perth.
13/03/17	EULAR Guidelines on Imaging Group - Zurich
27/03/17	PMRGCA NE Support Group Celebration - Gateshead
02/05/17	OMERACT webinar
08/05/17	EULAR Task Force on a GCA Registry - Zurich
16/05/17	Trustees Meeting - Dundee
23/05/17	OMERACT teleconference for PMR Group
01/06/17	OMERACT webinar for patient research partners.
09/06/17	Training Day on PMR and GCA for Fife Rheumatologists – St. Andrews.
14/06/17	CPG – Holyrood, Edinburgh.
04/07/17	OMERACT teleconference for PMR group
01/08/17	OMERACT webinar for patient research partners.
22/08/17	Trustees Meeting - Dundee
09/09/17	PMRGCAuk Members' Day – London.
13/09/17	CPG – Holyrood, Edinburgh
21/09/17	Angus Health Fair - Forfar
27/09/17	Highland Group Inaugural Meeting – Inverness.
01/11/17	Rheuma Roadshow, Kirkcaldy.
08/11/17	CPG – Holyrood, Edinburgh
28/11/17	Trustees Meeting - Dundee
Throughout	Members act as volunteer patients who help in the training of doctors in St. Andrews Medical School and Ninewells hospital, Dundee.

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

Involvement with research

PMR-GCA Scotland personnel are involved in many areas of research and development, both national and international.

Member of the EULAR task force producing recommendations for the use of imaging in the diagnosis and management of Large Vessel Vasculitis (which includes GCA). (Lorna Neill)

Member of the EULAR task force for setting up a GCA registry. (Lorna Neill)

Patient Research Partner in OMERACT Working Groups on PMR, Stiffness, and Glucocorticoid-related Adverse Events. (Lorna Neill)

Your Ears Project on hearing problems and GCA in collaboration with the Queen Elizabeth Hospital Gateshead and PMRGCAuk North East Support. (many members who volunteered)

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

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

OVERVIEW

In 2017 the charity continued to raise the profile of GCA and to advocate a Fast Track approach to its diagnosis and treatment.

From the start of the year in February, we were asked to assist Dr. Jane Gibson and the staff at Whyteman's Brae Hospital, Kirkcaldy in producing a holistic treatment pathway for those with PMR, GCA or both. The Chair spoke to the Rheumatology staff in February, then a group of members attended a Training Day in St. Andrews in June, where they described their personal experiences of living with PMR and/or GCA. This was used to produce treatment pathways for both PMR and GCA, including a pathway for flare.

In November a group of supporters heard Dr. Gibson present her work to a meeting of the Parliamentary Cross Party Group on Arthritis and Musculo-skeletal Conditions at Holyrood and show how fast-tracking patients in Fife with suspected GCA had reduced cases of sight loss so far this year to zero. After discussion with the Depute-Convenor, Rhoda Grant MSP, it was agreed that the CPG should send a letter to the Health Secretary encouraging this approach and asking for Scottish figures on sight loss due to GCA. This was done in January 2018 and we are awaiting a response.

Each year the charity attends the Angus Health Fair in September. Members from the Dundee Support Group use our stall to engage with members of the public and make the most of the networking opportunities with other charities and healthcare organisations. This has led to a request that we provide speakers at meetings of Angus Long Term Conditions Support groups in both Montrose and Carnoustie in the summer of 2018.

Our close alliance with PMRGCAuk, and again the support of Dr. Jane Gibson in Kirkcaldy, allowed us to benefit from a visit from The Rheuma Research Roadshow, a project funded by a grant from the Wellcome Trust and led by Kate Gilbert from the UK charity. On November 1st in the Victoria Hospital, Kirkcaldy, a large audience of medical professionals in the morning followed by an even larger public meeting in the afternoon, learned about both PMR and GCA and were brought up to date with our understanding of these illnesses and advances in their treatment.

Another objective, that of support for all those affected by PMR or GCA, was progressed by setting up a Support Group to cover Highland Region. After much preliminary work by David Carrott who had volunteered as Convener, the inaugural meeting was held in Inverness on 27th September with an attendance of ten which has been maintained since. As with our other groups, this number reflects the problems Highland group members face due to long travelling distances and adverse weather conditions, as many more are affiliated to the group but cannot always attend on the day. Highland group's existence has increased the charity's profile and membership in the area, not least by an article written by David which was published in the local press.

Raising awareness and educating both the public and the medical professionals is a major objective of the charity and I would like to thank those mentioned above and also so many of our members who have given of their time to assist in these projects and others. Our Helpline volunteers, Support Group Conveners and Trustees, especially those who hold the offices of Treasurer and Secretary, make the year's activities possible, as do the members who support our work in so many ways, not least in being there for each other to give advice, sympathy and encouragement whenever and wherever we meet.

LOCAL SUPPORT GROUPS

We now have four groups meeting regularly, monthly or bimonthly, in Dundee, Glasgow, Edinburgh and Inverness (Highland). Attendance at any meeting averages around ten, although many more (about a third of our

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

membership) are listed as group members. Some come regularly, some drop in from time to time. Socialising over tea and coffee or the occasional meal, sharing experience and mutual support form the content of the meetings. Speakers are invited from time to time on topics of interest such as Relaxation and Mindfulness or Seated Exercise.

We are still hoping that someone will be willing to act as local coordinator for a group in the Aberdeen area where there has been some interest from members. The charity has agreed to financially support new groups while they find their feet, should it be needed. Such expenses could include room hire, speaker expenses, publicity etc., although all groups are encouraged to become self-sufficient when possible.

Fuller and current information about all the Groups is available on the Website at

www.pmrandgca.org.uk/groups-and-contacts

HELPLINE

The charity has four volunteers located across Scotland who answer calls to the Helpline. This means that each volunteer will work for only one week in four, 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 and volunteer rota continues to be handled by Helen Faccenda. Before each trustees' meeting she highlights any difficulties or problems which have been encountered, and this continues to allow the system to be refined and the volunteers to learn from and support one another.

All volunteers are encouraged to attend appropriate courses, run by the Helplines Association, and expenses incurred are fully funded by the charity.

We received 193 calls during 2017, a few lasting 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 appears to remain steady throughout the year at about four calls a week, although more people are now choosing to email for information using the Website contact.

FACEBOOK and TWITTER

Find us www.facebook.com/pmrgcascotland/ and @pmrgcascotland.

INFORMATION PACKS, NEWSLETTERS and MEMBERSHIP

There were no changes in the contents of the packs in 2017. We mailed out 44 packs (down from 48 in 2016 and 60 in 2015). Requests for packs come from Helpline (16 in 2017), Website (12 in 2017) and a variety of other sources (16 in 2017). The number from other sources is higher than usual this year as there were six requests in December from the newly formed Highland Group. Feedback from recipients remains encouraging so the packs are a valuable part of the charity's offering

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 all documentation free of charge and continues to ensure that the enclosures are customised to the individual callers' needs wherever possible. The 2015 European League Against Rheumatism (EULAR) /American College of Rheumatology (ACR) recommendations for the management of polymyalgia rheumatica (PMR) were incorporated into the packs late in 2015.

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

337 copies of Newswire from PMRGCAuk, incorporating Scotland's newsletter, are mailed out by us 3 times a year. Of these 82% are sent to addresses in Scotland. The furthest away one is sent to Kenya. Of the 299 current members, 43% are in contact with us each year either by ringing the helpline, coming to the AGM or attending a Group Meeting. Over 65% are in contact over a two year period. Members are encouraged to get in touch regularly to ensure that they keep receiving mailings. Over a three year period there has been almost a 40% increase in the members living in Scotland and a 40% reduction in the number living in England.

We tend to lose over 10% of our membership each year due to death, recovery or getting the condition under control. This is more than matched by the increase in new members which is close to 15%. Therefore, in January 2015 we had 264 members and we now have 299. Almost a third of members are associated with one of the 4 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 an increasing number of new members. The number of unique visitors for the year has reached a new all-time high at nearly 17,000 (15,351 in 2016) and there are currently 13,800 "hits" a month (10,000 - restated - in 2016). Although most visitors are UK based, we do get contacts from elsewhere in the world and endeavour to help where possible.

The most popular pages are still 'Our PMR-GCA Stories and Yours' then the pages on Self Management and Coping Tips, the on-line version of Newswire, Research, and Management Guidelines for PMR and GCA.

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.

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.

Arthritis and Musculoskeletal Alliance (ARMA): Other than through collaboration with PMRGCAuk we no longer have membership of ARMA. We remain in touch directly with the other organisations such as the National Osteoporosis Society, Vasculitis UK, Arthritis Care and Research and the National Rheumatoid Arthritis Society.

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.

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 allows the charity to benefit from best practice experience and as a member is able to get a discount on training courses for our volunteers.

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

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.

FINANCIAL REVIEW

The Receipts and Payments Account shows a total surplus for the year of £7,276 compared to a total deficit last year of £4,612. Of this year's surplus, there is a surplus on Unrestricted Funds of £4,776 and a surplus on Restricted Funds of £2,500.

Income, at £13,342, was significantly ahead of last year. Following the issue of appeal letters to a number of charitable trusts, we had a wonderful response and total income from charitable trusts amounted to £10,500 in the year.

The support and generosity of these trusts, all of whom have supported us in the past, is hugely appreciated and without their continued support we would simply be unable to carry on the valuable work of the charity.

Our total costs were £3,359 lower than last year. We did not host a medical conference on PMR and GCA this year as we did last year in Glasgow at a cost of £1,811 and also no specific research grant was awarded this year. (Last year £1,500).

Our main costs of newsletters, stationery and postage were tightly managed and although the cost of hosting our AGM and conference in Edinburgh rather than Dundee was significantly higher than normal, we were able to meet our objective of attracting more members from the central belt of Scotland to this informative event in our calendar.

In the main, thanks to the ongoing support of a number of charitable trusts, the charity's finances are in a very strong position with total Restricted and Unrestricted Funds of £26,844 at the year end, which will enable the charity to continue its work in the coming years with confidence.

Lorna Neill, Chair

21 February 2018

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

Independent examiner's report to PMR-GCA Scotland

I report on the accounts of the charity for the year ended 31 December 2017 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
2. 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
Henderson Loggie
The Vision Building
20 Greenmarket
Dundee
DD1 4QB

21 February 2018

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

RECEIPTS AND PAYMENTS ACCOUNT

FOR THE YEAR ENDED

31 DECEMBER 2017

2016 £	RECEIPTS	2017 £	2017 £	2017 £
Total		Unrestricted	Restricted	Total
4,284	Donations	10,417	2,500	12,917
490	Gift Aid repaid	375	-	375
1	Bank Interest	-	-	-
38	Miscellaneous	50	-	50
4,813	Total receipts	10,842	2,500	13,342
	PAYMENTS			
1,710	Advertising/Information	348	-	348
1,019	Postage	1,082	-	1,082
704	Stationery	492	-	492
308	Delegate Expenses	221	-	221
25	Donations for Hall	50	-	50
44	Donations/Presentations	-	-	-
1,048	AGM and Annual Conference	1,917	-	1,917
1,811	Glasgow Medical conference	-	-	-
30	Support Groups	126	-	126
282	Insurance	322	-	322
-	Helpline Costs	125	-	125
275	Volunteer Expenses	765	-	765
151	Computer/website	166	-	166
140	Subscriptions	140	-	140
1,500	Research Grant Awarded	-	-	-
78	Miscellaneous expenses	-	-	-
9,125	Total payments for charitable activities	5,754	-	5,754
300	Examiner's fee	312	-	312
9,425	Total payments	6,066	-	6,066
(4,612)	Surplus/(deficit) for period	4,776	2,500	7,276

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

STATEMENT OF BALANCES AS AT 31 DECEMBER 2017

2016 £		2017 £
	<u>Bank and Cash Balances</u>	
24,180	At beginning of period	19,568
(4,612)	Surplus/(deficit) for period	7,276
19,568	At end of period	26,844
	<u>Reserves</u>	
17,568	Unrestricted reserves	22,344
2,000	Restricted reserves	4,500
19,568	Total reserves	26,844

-	<u>Assets</u>	-
	Computer and website	
	<u>Liabilities</u>	
312	Henderson Loggie - Independent Examiner's fee	325
	<u>Debtors</u>	
375	Gift Aid Repayment to 31 December 2017	435

Approved by the Management Committee and signed on their behalf on 21 February 2018

Lorna Neill, Chair

PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

ANNUAL REPORT AND ACCOUNTS

NOTES TO THE ACCOUNTS

FOR THE YEAR TO 31 DECEMBER 2017

1. No member of the Management Committee received remuneration.
2. Mrs Lorna Neill received reimbursement of £211 (2016 - £185) in respect of costs incurred by her during the year. Of this £34 related to operational costs and £177 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland activities.

Mr J Michael Benneworth received reimbursement of £2,016 (2016 - £2,631) in respect of costs incurred by him during the year. Of this £1,867 related to operational costs and £149 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland activities.

No other trustee received any reimbursement of expenses.