



**POLYMYALGIA RHEUMATICA and GIANT CELL ARTERITIS SCOTLAND**

**(PMR-GCA SCOTLAND)**

**Scottish Charity Number: SC037780**

**Report and Accounts**

**for the year ended 31 December 2016**

## PMR-GCA SCOTLAND

Scottish Charity Number: SC037780

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|  |                        |  |            |               |
|--|------------------------|--|------------|---------------|
| <b>OFFICERS<br/>including<br/>Management<br/>Committee</b> | Chair and Principal    | Mrs Lorna Neill                                    | Re-elected | 19 April 2016 |
|  | Registered Address     | 7 Hamilton Place<br>Perth<br>Perthshire<br>PH1 1BB |            |               |
|  | Secretary              | Mr Michael<br>Benneworth                           |            |               |
|  | Treasurer<br>Committee | Mr Harvie Findlay<br><br>Currently no<br>members   |            |               |

Mrs Bea Nicholson resigned as a trustee and as chair on 30 September 2016. Following her retiral, Mrs Lorna Neill was appointed interim chair and Mr Michael Benneworth was appointed interim secretary with effect from 1 October 2016.

Mrs Lorna Neill is available for re-appointment as chair.

Mr Michael Benneworth retires by rotation and is available for re-election as a trustee and for re-appointment as secretary.

Mrs Sarah Gray resigned as a trustee on 19 April 2016.

**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 2016.

**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.

**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. 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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| <b>Date</b> | <b>The Chair, and/or an assigned depute, attended or took part in the following:</b>  |
|-------------|---|
| 12 Jan 2016 | Edinburgh Support Group lunch.  |
| 13 Jan 2016 | GCA Guidelines Panel – webinar.   |
| 16 Feb 2016 | Trustees Meeting – Dundee.  |
| 19 Feb 2016 | Glasgow Support group meeting.  |
| 29 Feb 2016 | Fundraising Training – Glasgow (2 days).  |
| 02 Mar 2016 | CPG - Holyrood, Edinburgh.  |
| 09 Mar 2016 | GCA Guidelines Panel Meeting – Southend.  |
| 25 Apr 2016 | OMERACT webinar.  |
| 26 Apr 2016 | BSR Conference – Glasgow (3 days).  |
| 10 May 2016 | OMERACT Conference – Canada (7 days).   |
| 03 Jun 2016 | EULAR Guidelines on Imaging Group – Zurich.   |
| 08 Jun 2016 | EULAR Study Group – London.   |
| 14 Jun 2016 | Trustees Meeting – Dundee.  |
| 16 Aug 2016 | Trustees Meeting – Dundee.  |
| 03 Sep 2016 | Glasgow Support Group meeting.  |
| 14 Sep 2016 | CPG – Holyrood, Edinburgh.  |
| 22 Sep 2016 | Angus Health Fair.  |
| 27 Sep 2016 | GCA Guidelines Panel webinar.   |
| 30 Sep 2016 | PMR-GCA Scotland Conference for medical professionals – Glasgow.  |
| 11 Oct 2016 | Glasgow Support Group meeting.  |
| 15 Nov 2016 | Trustees Meeting – Dundee.  |
| 23 Nov 2016 | AGM of Dundee Voluntary Action.   |
| 06 Dec 2015 | Scottish Health Council and The Alliance meeting ‘Our Voice’ – Glasgow.   |
| Throughout  | Members act as volunteer patients who help in the training of doctors in St. Andrews Medical School and Ninewells hospital, Dundee. |

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### **Involvement with research**

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

With Sarah Mackie at Leeds (research studies in PMR) (Lorna Neill)

With Emma Harris at Leeds (exercise and PMR): STAY ACTIV and FACT (Lorna Neill)

With Louise Sorensen at Leeds (how research is presented on the Internet): IN THE LOOP (Lorna Neill and Sarah Gray)

Dr. Jo Robson at Bristol (Patient reported outcomes for GCA and Exercise and GCA) (Sarah Gray and Caro Wilkinson)

Member of the group looking at new guidelines for GCA chaired by Prof Dasgupta (Lorna Neill and Sarah Gray)

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

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

### **Acronyms and abbreviations**

CPG                Scottish Parliament's Cross Party Group on Musco-Skeletal Conditions

OMERACT        International collaboration on Outcome Measures in Rheumatology

BSR                British Society for Rheumatology

EULAR            European League Against Rheumatism

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## OVERVIEW

As always, the charity put its efforts in 2016 into support for members through the Groups, the Helpline and the Website. What we can do is limited by the number of members willing and able to help out in these activities and on the Committee and in the latter part of the year this had fallen to the minimum required. By the end of the year however a number of new volunteers from all over the country were attending meetings and helping with tasks. With their assistance and that of other like-minded members we shall continue to meet our objectives in the coming year.

Bea Nicholson as Chair organised a very successful conference in Glasgow in September, with the purpose of introducing the new Guidelines for PMR and GCA to medical professionals in the area of Greater Glasgow and Clyde and in addition to raise the Charity's profile in this region. Both aims were met; about sixty attended; the evaluations were positive and the event came in below budget. We hope to follow up on this during 2017 by continuing to press for Fast Track Pathways for patients with suspected GCA whenever we can get or make the opportunity.

Policies are regularly reviewed and updated as necessary. In June, the revised Data Protection and Confidentiality policy was brought into use.

Again, we were able to make a financial contribution to research. A donation of £1500 was given to Dr Sarah Mackie of Leeds University Hospitals Trust for work relating to PMR/GCA. In addition, many members took part in focus groups and acted as volunteer patients and patient research partners, working with researchers in Scotland and further afield.

## LOCAL SUPPORT GROUPS

There are currently three groups in Scotland that meet regularly. Size varies greatly and a small cafe meeting is as valuable as a large meeting with a speaker. 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 are encouraged to become self-sufficient when possible.

The Charity is still hoping that someone will be willing to act as local coordinator for a group in the Aberdeen or Inverness area where there has been some interest from members.

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

## DUNDEE

Group membership is around forty although attendances fluctuate, with numbers dropping to a dozen in the summer and rising to about twenty over the winter. Group finances are still very healthy. Our small regular income from a voluntary tea/coffee donation is supplemented by the proceeds of Calceos tubes filled with 20p coins by members. This has allowed us to make a donation of £125 to PMR-GCA Scotland and to recompense Dundee Parish Church (St. Mary's) for their kindness in allowing us to use one of their rooms.

As well as learning from each other at every monthly meeting, we have had speakers on Living with a Chronic Illness, Complimentary Therapies and Occupational Therapy and, as always, enjoyed socialising at a lunch in March, organised by Margaret Maloney, and at our Christmas party in December. Further details and times of the monthly meetings can be found on our website or by phoning the Helpline.

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## EDINBURGH

Group numbers have increased this year. There are now 17 members of this group with an average turnout to meetings of about 12. Generally, they update each other on their own health and how their medication is helping. New members are encouraged to share their experiences. A local coordinator manages the day-to-day organisation and the group has increased the frequency of meeting to monthly, in the Undercroft Cafe, St Andrew's & St George's Church, George Street.

## GLASGOW

Membership has increased, with about six attending on any given date. They talk about any new information on PMR/GCA that they have read or heard of. They also discuss their own health and how their medication is helping. A local coordinator manages the day-to-day organisation and the group meets alternate months in the offices of The Health and Social Care Alliance Scotland (The ALLIANCE), Venlaw Building, 349 Bath Street, Glasgow G2 4AA.

## HELPLINE

The charity has managed to maintain 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 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 175 calls during 2016, many lasting nearly an hour, although simple enquiries can be dealt with more quickly. Some of these are new callers, some repeat calls and there are a few random sales 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 although there is an impression that in recent years more people are choosing to ask for information using the Website contact.

## INFORMATION PACKS and NEWSLETTERS

The packs contain a variety of information from various sources. There are 2 different packs – a standard pack which most people get 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 the individual caller's needs wherever possible.

48 packs were mailed to callers during the year compared to 60 in 2015. This may be because all the information is also available on line if the caller prefers. Feedback from recipients remains encouraging so the packs are a valuable part of the charity's offering.

We continue to write a specifically Scottish page for Newswire which is otherwise produced by PMRGAuk. An average of 320 copies of these newsletters are sent out 3 times a year to our members. Of these over 75% are distributed within Scotland. The furthest one is sent to Kenya. Some copies are handed out or sent by email. Of the 294 current members, 220 of whom are in Scotland, more than half are in contact with us each year either by

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ringing the Helpline, coming to the AGM or attending a Group Meeting. Over 75% are in contact over a 2-year period. Members are encouraged to get in touch regularly to ensure that they keep receiving mailings.

## 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 an increasing number of new members. The number of unique visitors for the year has reached a new all-time high at over 15,000 and there are currently over 2,500 "hits" a month. Although most visitors are UK based, we do get contacts from elsewhere in the world and endeavour to help where possible.

The most popular page is still 'Our PMR-GCA Stories and Yours' with increasing numbers accessing pages on Self Management, the on-line version of Newswire 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. patient.co.uk or PMRGCAuk.

The charity still believes that its offering is unique and that our annual hosting fee 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. ARMA Scotland has not held meetings this year and its future is uncertain although we remain in touch with the other organisations such as Arthritis Care, the National Osteoporosis Society, Arthritis 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.

**Cross Party Group (CPG):** PMR-GCA Scotland retains its membership of the Arthritis and Musculoskeletal Conditions group. 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. The chair and others have attended where possible.

**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.

**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.

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### **FINANCIAL REVIEW**

The Receipts and Payments Account shows a total deficit for the year of £4,612. Of this, there is a deficit on Unrestricted Funds of £1,973 and a deficit on Restricted Funds of £2,639.

The charity's finances are in a strong position and we did not actively seek donations from charitable trusts, our main source of funding. Against that our costs included for the first time the costs of hosting a major conference in Glasgow (£1,811) designed to target medical professionals in the area and to raise awareness of the charity in the region. We believe both objectives were achieved. As a consequence, therefore, an overall deficit of £4,612 arose but this was wholly expected and able to be met given our level of reserves.

During the year, we received total donations of £4,284 of which £2,000 represented donations from Charitable Trusts. We sincerely hope that we can rely on the support of trusts in the coming years as the requirement arises so that we can continue the good work of the charity.

Our main ongoing costs continue to be stationery, postage, newsletters and leaflets required to keep our members well informed and these costs did rise compared to last year. The cost of our AGM and annual conference also rose this year but continues to be informative to members and well supported.

In addition to our operational costs, we made a research donation to Dr Sarah Mackie at Leeds University Trust to assist her valuable ongoing research into PMR and GCA and as noted above we held a special conference in Glasgow, with both items adding significantly to our overall costs.

At the year end the organization had total Restricted and Unrestricted Funds of £19,568, which still places the charity in a sound position to continue its work in the coming years.

**Lorna Neill, Chair**

**25 January 2017**

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### Independent examiner's report to PMR-GCA Scotland

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I report on the accounts of the charity for the year ended 31 December 2016 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

25 January 2017

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**RECEIPTS AND PAYMENTS ACCOUNT**

**FOR THE YEAR ENDED**

**31 DECEMBER 2016**

| 2015<br>£    | RECEIPTS  | 2016<br>£      | 2016<br>£      | 2016<br>£      |
|--------------|---|----------------|----------------|----------------|
| Total        |   | Unrestricted   | Restricted     | Total          |
| 7,277        | Donations                                       | 4,284          | -              | 4,284          |
| 355          | Gift Aid repaid                                 | 490            | -              | 490            |
| -            | Bank Interest                                   | 1              | -              | 1              |
| 52           | Miscellaneous                                   | 38             | -              | 38             |
| <b>7,684</b> | <b>Total receipts</b>                           | <b>4,813</b>   | <b>-</b>       | <b>4,813</b>   |
|              | <b>PAYMENTS</b>                                 |                |                |                |
| 1,197        | Advertising/Information                         | 615            | 1,095          | 1,710          |
| 388          | Postage   | 523            | 496            | 1,019          |
| 949          | Stationery                                      | 704            | -              | 704            |
| 750          | Delegate Expenses                               | 308            | -              | 308            |
| 50           | Donations for Hall                              | 25             | -              | 25             |
| -            | Donations/Presentations                         | 44             | -              | 44             |
| 754          | AGM and Annual Conference                       | -              | 1,048          | 1,048          |
| -            | Glasgow Medical conference                      | 1,811          | -              | 1,811          |
| 74           | Support Groups                                  | 30             | -              | 30             |
| 317          | Insurance                                       | 282            | -              | 282            |
| 349          | Volunteer Expenses                              | 275            | -              | 275            |
| 138          | Computer/website                                | 151            | -              | 151            |
| 248          | Subscriptions                                   | 140            | -              | 140            |
| 1,500        | Research Grant Awarded                          | 1,500          | -              | 1,500          |
| -            | Miscellaneous expenses                          | 78             | -              | 78             |
| <b>6,714</b> | <b>Total payments for charitable activities</b> | <b>6,486</b>   | <b>2,639</b>   | <b>9,125</b>   |
| 288          | Examiner's fee                                  | 300            | -              | 300            |
| <b>7,002</b> | <b>Total payments</b>                           | <b>6,786</b>   | <b>2,639</b>   | <b>9,425</b>   |
| <b>682</b>   | <b>Surplus/(deficit) for period</b>             | <b>(1,973)</b> | <b>(2,639)</b> | <b>(4,612)</b> |

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**STATEMENT OF BALANCES AS AT 31 DECEMBER 2016**

| <b>2015<br/>£</b> |                                     | <b>2016<br/>£</b> |
|-------------------|-------------------------------------|-------------------|
|                   | <b><u>Bank and Cash Balance</u></b> |                   |
| <b>23,498</b>     | At beginning of period              | <b>24,180</b>     |
| <b>682</b>        | Surplus/(deficit) for period        | <b>(4,612)</b>    |
| <b>24,180</b>     | <b>At end of period</b>             | <b>19,568</b>     |
|                   | <b><u>Reserves</u></b>              |                   |
| <b>19,541</b>     | Unrestricted reserves               | <b>17,568</b>     |
| <b>4,639</b>      | Restricted reserves                 | <b>2,000</b>      |
| <b>24,180</b>     | <b>Total reserves</b>               | <b>19,568</b>     |

|            |   |            |
|------------|---|------------|
|            | <b><u>Assets</u></b>                          |            |
| <b>-</b>   | Computer and website                          | <b>-</b>   |
|            | <b><u>Liabilities</u></b>                     |            |
| <b>295</b> | Henderson Loggie - Independent Examiner's fee | <b>312</b> |
|            | <b><u>Debtors</u></b>                         |            |
| <b>490</b> | Gift Aid Repayment to 31 December 2016        | <b>375</b> |

Approved by the Management Committee and signed on their behalf on 25 January 2017

Lorna Neill, Chair

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### **NOTES TO THE ACCOUNTS**

#### **FOR THE YEAR TO 31 DECEMBER 2016**

1. No member of the Management Committee received remuneration.
2. During her period as a trustee, Mrs Bea Nicholson received reimbursement of £3,181 (2015 - £1,596) in respect of costs incurred by her during the year. Of this £2,874 related to operational costs and £307 related to travel and hotel costs incurred carrying out duties in connection with PMR-GCA Scotland activities.

Mrs Lorna Neill received reimbursement of £185 (2015 - £445) in respect of costs incurred by her during the year. Of this £44 related to operational costs and £141 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland activities.

During her period as a trustee, Mrs Sarah Gray received reimbursement of £nil (2015 - £117) in respect of travel costs incurred by her during the year.

Mr J Michael Benneworth received reimbursement of £2,631 (2015 - £1,598) in respect of costs incurred by him during the year. Of this £2,610 related to operational costs and £21 related to travel costs incurred carrying out duties in connection with PMR-GCA Scotland activities.

No other member of the committee received any reimbursement of expenses.