



**Accounts
and
Annual Report
2023-2024**

Message from Chair of Trustees

Whenever I write this annual message I am amazed how much has changed in a year. although our core aims to support our members and facilitate improvements in the management of PMR and GCA remain unaltered. It has been a busy year again.

At the time of our annual general meeting last year we said goodbye to Candy Horsbrugh who was our director for over five years, steered us through the Covid-19 years, and did so much to innovate and to improve what we do. But we were very lucky to attract Sophie Boyce as our new director and she is proving a brilliant choice. We have also had changes on the trustee board. We said goodbye to Chris Young who in particular steered the helpline for many years, and Sara Muller who provided invaluable scientific advice to the board and shaped our research agenda, and last but not least we also said goodbye to Penny Denby who not only chaired the board of trustees, but was immensely active in organising events and expanding groups in Kent and South London. We miss them but have been very pleased to welcome new trustees – Fiona Johnson, Gail Booth and Bill Mansfield – and their biographies can be found on the website.

Specific important initiatives include our participation in a research project intriguingly named the PMR Paradox, looking at why there seem to be fewer cases of PMR in the north of England compared with the south. With Dr Sarah Mackie from Leeds, well known to most of you from her webinars and contributions to Newswire, we were successful in our application to the prestigious NIHR, the National Institute for Health Services Research, to look into this. As a result we now have a research fellow, Lucas Coutin, in the team.

The research projects we funded ourselves, thanks to a very generous donation from one of our members, have come to fruition. Dr Max Yates, in Norwich, has completed his research into exactly how corticosteroids are being used in the treatment of polymyalgia rheumatica, and we have published the evidence-based exercise advice leaflet created by Dr Anne O'Brien and her colleagues in Keele University.

Please look into the details of everything we do in this report. But when I say 'we', we are of course dependent on all of you, especially those of you who volunteer in so many different ways. We are hugely grateful for all that help. But we always seek to recruit more, especially for our telephone helpline and group organisers. If you are interested, please drop us an email – info@pmrgca.org.uk.

Humphrey Hodgson

Chair of Trustees

Membership

Membership – our driving force.

Our members aren't just vital to the work we do, they are the reason we exist. Our members shape our services and strategy, they are our best ambassadors, and we are always bowled over by their generosity in sharing their time and experience to help others. They volunteer, participate in research, raise awareness and fundraise.

We keep our membership fee as low as possible, and by the end of March 2024 we had 1600 members, of which 449 were new members during 2023/2024. This includes patient, friend and professional members.

'Just knowing that I was among so many others either suffering like me or understood our suffering was a great comfort to me. Knowing you were there if I wanted you!'

'It made me feel that I was heard. It helped me understand my condition better. It altered my mindset that I should be able to do everything I was able to do before I was diagnosed. it helped me to explain to others how the condition affected me.'

'Knowing I'm not alone. Having never heard of PMR and being diagnosed during lockdown the charity and Kate Gilbert's book became my support system.'

'Easy and comprehensive access to a wealth of information whether from fellow sufferers/the professionals and the charity itself has been invaluable. I never feel as if I'm alone in this.'

Members' Day

Our 2023 Members' Day and AGM took place online again. Our speakers were Dr Lorraine Watson, Professor Hector Chinnoy and Will Gregory, and Dr Leah Bousie.

Dr Lorraine Watson, Clinical Dietician from Keele University Medical School, spoke about managing appetite and maintaining a healthy weight. The talk touched on portion control, balanced meals and healthy snacking, with a Q&A that included discussions about comfort eating and eating the right foods to limit the increased hunger some people experience while on steroids.

Professor Hector Chinnoy, Consultant Rheumatologist at Salford Royal NHS Foundation Trust, and Will Gregory, Consultant Physiotherapist at Salford Royal and Vice President of the British Society of Rheumatology, gave a talk on muscle weakness and improving muscle strength, general fitness and balance through exercise.

Dr Leah Bousie, Clinical Psychologist at Central London Community NHS Trust, spoke about the affects steroid use can have on our ability to regulate mood, the way our bodies regulate emotion, and steps we can take to manage and improve our mood and motivation.

All of our speakers were so generous in giving their time to make Members' Day varied and informative for those that attended or watched the recording afterwards.

'I found it all interesting and particularly found the mindfulness presentation useful.'

'It was a very well balanced and informative event. Excellent to have it on Zoom. Good Q&A via chat. Each guest was excellent. Good to have experts in their field. The timings were good so that people didn't waffle, were concise but got points across.'

'Being able to ask questions in the chat from the experts, particularly the two guys from Salford about muscle, bone, exercise. Not often you get direct access to such experts!'

'All speakers were exceptionally good, thank you, with "down to earth" language everyone could understand. It made me realise that I am not just imagining all the things I suffer from.'

PMRGCAuk Week 2023

PMRGCAuk week 2023 remained online in June. We had two great guest speakers and more than 320 members and guests to our PMRGCAuk week webinars.

Ramona Tinei, Regional Fitness Lead in the south for Nuffield Health, gave a talk on the Nuffield Joint Pain Programme, which a number of PMRGCAuk members have taken part in. The programme is a clinically designed intervention providing a mix of education, physical activity and wellbeing support designed to help people become more active. It is a free programme that runs for six months.

Dr Ben Mulhearn, Rheumatology Registrar and Academic Clinical Fellow at Bath University, spoke about GCA. His talk covered the potential causes of GCA, the progress being made on diagnosis, and research he is involved with into reducing the complications of GCA.

Thank you to all our members who got involved with fundraising and awareness-raising efforts during PMRGCAuk week, which included coffee mornings, bake sales, an open studio art sale, obstacle runners and more.

'This webinar was one of the very best I've seen. Dr Mulhearn was very approachable and used visuals and language that were easy to understand.'

'I was particularly interested in the GCA seminar. The speaker was excellent and I learned a lot. I get a sense of the science moving on and we are privileged to hear about developments early. I sent the link to my rheumatologist.'

'Well presented with helpful information for self-help.'

Providing support and information

We provide support through our Telephone Helpline, our national network of Support Groups, through our online forum through HealthUnlocked, and on our own website and social media feeds.

Telephone Helpline

Our telephone helpline team take calls from Monday to Friday, 9am to 5pm, and callers are invited to leave their details for a call back if their call can't be answered immediately. The team consists of six volunteers: Monica Alderton, Stephanie Beer, Trish Galli, Fiona Johnson, Yvonne McGowan and Chris Young who have all experienced PMR or GCA, and we can't thank them enough for the vital support they provide to callers.

Until recently the organisation of the rotas for the volunteer team alongside other administrative tasks was undertaken by Chris Young who had been a member of the Helpline team since its original inception. Chris stepped down from this role in September 2023, but remains a key part of the team and Fiona Johnson who has taken on the administrative functions is very grateful for her continued commitment to the Helpline.

The Helpline team has continued to work with trainer Alice Hanscomb (thanks to grant support) and this has enabled the volunteers to develop their skills and to improve their practice.

The Helpline volunteers spoke to 356 callers from April 2023 to March 2024, with slightly fewer calls received in December than the rest of the year.

Statistics

- 74% of callers had PMR; 16% GCA; 10% had both. This is a very similar spread to 2022/2023.
- The average age of callers was 76 years old.
- 76% of callers were female; 24% male.
- 43% of callers were newly or recently diagnosed; 40% had been diagnosed between 1-4 years and 12% had been diagnosed over five years. 5% of callers did not disclose how long they had been diagnosed or were calling on behalf of someone else.
- 67% of people we spoke to were first time callers, and 33% of all callers had called more than once.
- 88% of callers were seeking more information and at the end of their call many were directed to our website for more information or sent an information pack.
- 45% of callers wanted to talk about prednisolone in general, with 51% wanting to talk more specifically about steroid tapering and 11% about steroid sparing drugs.
- 58% of callers expressed that they wanted to talk about their concerns with someone who understands what they are going through and has experience of the condition(s) and of being on long-term steroids. This is an increase from just under 50% last year.
- 17% of callers shared that they felt unhappy, dissatisfied or angry before calling.
- 28% of callers are recorded as being members of PMRGCAuk, which is an increase from 20% in 2022/2023.

Support groups

Our local support groups remain a valuable resource for members and non-members around the country. Not only do they offer much needed support to those that attend, but they also help to grow the reach of the charity and spread awareness of PMR and GCA.

2022-2023 saw the re-emergence of more in-person support groups as we moved further away from the pandemic and 2023-2024 has seen many of these groups thrive and grow. There continues to be a great diversity in the make-up and organisation of the support groups. The preferred way forward seems to be the relaxed meet-up – often in a local coffee shop or small community venue – where members can talk about their shared experiences in a relaxed and friendly environment. Some groups continue to organise guest speakers and workshops, which are immensely valued by those that attend, especially when there is a supportive local rheumatology department that is able to engage with meetings.

Online meetings continue to be important, especially for those that don't have a local support group or aren't able to attend their local group in-person.

Throughout the year there continued to be dedicated support offered to the group organisers by Neelam Russell, funded by grants from Kent Community Foundation (£4857) and Sevenoaks Community Foundation (£1400). We continue to update our website with details of each group's next meeting and support GOs to advertise their groups locally.

We are always warmed to hear the positive impact people have felt from attending a support group and we cannot thank our GOs enough for making them possible.

'The meetings are very good and continue to develop.'

'The group I attend is excellent. Literature is available and we hopefully help and support each other by talking about our experiences.'

'I went to one and everyone was friendly and supportive.'

PMRGCAuk Information Packs

Our information packs continue to be a popular resource, with the total number of packs requested in 2023-2024 representing a 52% increase on 2022-2023's figures. The information packs can be requested online through our website, and requests also come in through the telephone helpline and direct to the office via email or telephone.

The packs are available as a digital copy – which is sent automatically when a request is made through the website, and in hard copy. They consist of information about the charity, our *Symptoms* and *How We Can Help* leaflets, booklets produced in conjunction with Versus Arthritis, British Society for Rheumatology (BSR) guidelines on PMR and GCA, and details of how to join the charity.

2020/2021

Total information packs requested: 603

Hard copy: 171

Digital copy: 432

2021/2022

Total information packs requested: 866

Hard copy: 303

Digital copy: 563

2022/2023

Total information packs requested: 1046

Hard copy: 342

Digital copy: 704

2023/2024

Total information packs requested: 1590

Hard copy: 349

Digital copy: 1241

Our thanks go to Laurene Brooks, who volunteers her time to send out all hard copy information packs and track the information and figures on packs sent out.

HealthUnlocked Forum

Our PMRGCAuk forum is provided through the HealthUnlocked platform. It is a patient-led community that allows members to share their experiences and seek support from others who have, or have had, PMR/GCA.

You don't have to be a member of the charity to access the forum and it has members from around the globe. It is a very active forum with a mix of longstanding and regular users, and those that drop in more irregularly.

At the end of March 2024, we had 4,513 active members. This number is based on the number of people that have logged onto HealthUnlocked in the past month, and it fluctuates throughout the year. There was an average of around 195 new members signing up each month.

In March 2024, there were 348 posts (threads) made on the forum, inviting a total of 6293 replies from members.

HealthUnlocked is administrated and moderated by PMRGCAuk staff and volunteers. We are very grateful for all the support we receive on HealthUnlocked, but particularly to our volunteers known as PMRPro and DorsetLady who work tirelessly to ensure the smooth running of the forum.

'I find it very responsive and informative.'

'This was a lifesaver for me. I found it after reading Kate Gilbert's book, which I ordered on Amazon. I had never heard of PMR before getting diagnosed by my GP.'

'I have learnt more from the contributors to HealthUnlocked than anyone else.'

PMR Myth Busting Campaign

In August 2023 we launched the PMR Myth Busting Campaign – a digital campaign to raise awareness of PMR in general, and specifically to dispel some of the myths that patients often encounter.

We worked on the project with Dr Sarah Mackie and an involved patient group to understand which myths and misconceptions we should focus on. We worked with graphic designer Vince Walden, who generously volunteered his time, to produce four infographics that were promoted across our website, social media and email.

We are very grateful to everyone who got involved whether it was in the patient focus groups, or sharing our emails, tweets and posts. We reached tens of thousands of people, generated in excess of 2,500 clicks on our website and generated lots of discussion.

We give particular thanks to Joan Binns, a former member, who made this work possible by leaving a legacy donation to us in her will.

‘Thanks so much for trying to bring PMR into everybody's radar as it is an unknown illness for the majority of the population.’

‘Brilliant, just seen the post on Twitter and I liked and retweeted it straight away.’

Research and awareness

In 2021, PMRGCAuk received a generous donation from one of our members who wanted to fund research into PMR. This year saw the fruition of the work funded by this donation.

In January, we were delighted to launch the new booklet *Maintaining movement, activity and exercise with PMR* produced by Dr Anne O'Brien, Senior Physiotherapy Lecturer at Keele University, and developed alongside a team of professionals from Keele and Leeds Universities and patient involvement. The booklet is available to download from our website with print copies available on request. Exercises included in the booklet are also suitable for those with GCA.

Dr Max Yates also completed his study of those living with PMR in England who are part of the ECLIPSE live database used by the NHS. The work looked to better understand steroid prescriptions for those with PMR, whether they fall in line with best practice guidelines for long term steroid exposure, and how this data can be more easily tracked and monitored by healthcare professionals. Dr Yates is continuing to work with PMRGCAuk and ECLIPSE on future grant submissions to improve the way PMR is managed nationally.

In September, we also began work on an NIHR funded research project in collaboration with Keele and Leeds Universities. The PMR Paradox project will run until March 2025 and looks to better understand why there are fewer diagnoses of PMR in the north of England than the south, when global data suggests that prevalence increases the further you go from the equator. We have employed Lucas Coutin to work on the project as our Northern Outreach Lead.

'The exercise booklet has been invaluable to me – could not possibly be improved!'

Financial Review

This year we recorded a deficit on all activities of £23,748. This is a slightly smaller deficit than last year (£26,185) and is consistent with our strategy of increasing services by utilising the money received from legacies in earlier years.

Income

Income for the year was £116,645. Our main source of income is the subscriptions and donations of the charity's members and supporters which totalled £71,375 and represents a healthy increase of almost 20% over the previous year.

We received £14,513 from two legacies, £17,330 from the PMR Paradox project with Leeds University, £8,111 of interest on the investment of our surplus funds and £5,316 from fundraising and other activities.

Expenditure

Expenditure for the year was £140,393 of which the major cost was salaries totalling £100,689. Expenditure on restricted funds included the funding for our support group networks in Kent and Sussex, a grant of £9,700 to Keele University for the production of the PMR Exercise Booklet and funding the helpline volunteer training programme.

Balance Sheet

As a result of the deficit incurred in the year, total funds reduced by £23,748 to £215,625. The trustees will continue to use these reserves and future income to support the needs of its members and to develop the services for its members in a sustainable way.

Reserves analysis

During the year the Legacy Reserve reduced by £7,575, Restricted Reserves reduced by £20,194 and the General Reserve increased by £4,021 to £73,334 and remains consistent with the reserves policy to maintain at least three to six months of operating costs in line with Charity Commission guidance.

Reserves Policy

Charities are required to have a reserves policy to show they have sufficient reserves to continue to meet their obligations and to show that excess reserves are not being held. The trustees have resolved to maintain the following reserves out of unrestricted funds.

1. General Reserve

The trustees have resolved that the general reserve should be sufficient to meet three to six months of the charity's ongoing operating costs.

2. Legacies Reserve

The trustees have resolved to create a specific Legacies Reserve, the purpose of which is to enable the trustees to manage large unrestricted legacies in an efficient and effective manner to best promote the charity's objectives and the public benefit. This policy provides

for the steady and controlled release of such funds into the charity's general reserves in order to avoid the financial distortions and instabilities which can be created by the irregular and unexpected receipt of significant legacies.

The Trustees have established the following principles to apply to the Legacy Reserve:

- The first £5,000 of any individual unrestricted legacy will be treated as part of the General Reserve and any excess over £5,000 will be added to the Legacies Reserve.
- At the start of each financial year one-eighth of the remaining balance of each legacy previously added to the Legacies Reserve will be released to the General Reserve.

This policy was introduced with effect from 01 April 2020.



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
Polymyalgia Rheumatica and Giant Cell Arteritis UK

On accounts for the year
ended

31st March 2024

Charity no
(if any)

1128723

Set out on pages

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2023.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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

Signed:

Date: 30/07/2024

Name:

Katherine Dawn Gamage CGMA

Relevant professional
qualification(s) or body

Associate Member of the Chartered Institute of Management Accountants (ACMA, CGMA)

Address:

8 Pemscott Close


Alvescot, Bampton

OX18 2QE

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

Statement of Financial Activities

 CHARITY COMMISSION FOR ENGLAND AND WALES	PMRGCAuk			Charity No (if any)	1128723	
				Company No	6763889	
	Annual accounts for the period					
	Period start date	01/04/2023	To	Period end date	31/03/2024	

Section A Statement of financial activities (including summary income and expenditure account)						
Recommended categories by activity	Guidance Notes	Unrestricted funds £ F01	Restricted income funds £ F02	Endowment funds £ F03	Total funds £ F04	Prior year funds £ F05
Incoming resources (Note 3)						
Income and endowments from:						
Donations and legacies	S01	85,887	-	-	85,887	59,957
Charitable activities	S02	21,847	-	-	21,847	11,749
Other trading activities	S03	799	-	-	799	1,983
Investments	S04	8,112	-	-	8,112	3,809
Separate material item of income	S05	-	-	-	-	-
Other	S06	-	-	-	-	-
Total	S07	116,645	-	-	116,645	77,498
Resources expended (Note 4)						
Expenditure on:						
Raising funds	S08	27,862	-	-	27,862	15,675
Charitable activities	S09	87,095	10,492	-	97,587	84,313
Separate material item of expense	S10	-	9,702	-	9,702	-
Other	S11	5,242	-	-	5,242	3,695
Total	S12	120,199	20,194	-	140,393	103,683
Net income/(expenditure) before tax for the reporting period	S13	- 3,554	- 20,194	-	- 23,748	- 26,185
Tax payable	S14	-	-	-	-	-
Net income/(expenditure) after tax before investment gains/(losses)	S15	- 3,554	- 20,194	-	- 23,748	- 26,185
Net gains/(losses) on investments	S16	-	-	-	-	-
Net income/(expenditure)	S17	- 3,554	- 20,194	-	- 23,748	- 26,185
Extraordinary items	S18	-	-	-	-	-
Transfers between funds	S19	-	-	-	-	-
Other recognised gains/(losses):						
Gains and losses on revaluation of fixed assets for the charity's own use	S20	-	-	-	-	-
Other gains/(losses)	S21	-	-	-	-	-
Net movement in funds	S22	- 3,554	- 20,194	-	- 23,748	- 26,185
Reconciliation of funds:						
Total funds brought forward	S23	182,012	57,361	-	239,373	265,558
Total funds carried forward	S24	178,458	37,167	-	215,625	239,373

Balance Sheet

Charity Name PMRGCAuk

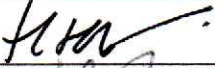
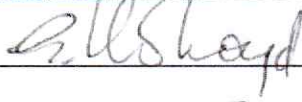
Charity No
Company No

1128723
6763889

Section B Balance sheet

	Guidance Notes	Unrestricted funds £ F01	Restricted income funds £ F02	Endowment funds £ F03	Total this year £ F04	Total last year £ F05
Fixed assets						
Intangible assets	B01	-	-	-	-	-
Tangible assets	B02	-	-	-	-	-
Heritage assets	B03	-	-	-	-	-
Investments	B04	-	-	-	-	-
Total fixed assets	B05	-	-	-	-	-
Current assets						
Stocks	B06	-	-	-	-	-
Debtors (Note 7)	B07	29,329	-	-	29,329	8,283
Investments	B08	138,032	28,747	-	166,779	181,272
Cash at bank and in hand	B09	14,746	8,420	-	23,166	52,740
Total current assets	B10	182,107	37,167	-	219,274	242,295
Creditors: amounts falling due within one year (Note 8)	B11	3,649	-	-	3,649	2,922
Net current assets/(liabilities)	B12	178,458	37,167	-	215,625	239,373
Total assets less current liabilities	B13	178,458	37,167	-	215,625	239,373
Creditors: amounts falling due after one year	B14	-	-	-	-	-
Provisions for liabilities	B15	-	-	-	-	-
Total net assets or liabilities	B16	178,458	37,167	-	215,625	239,373
Funds of the Charity						
Endowment funds	B17	-	-	-	-	-
Restricted income funds (Note 9)	B18	-	37,167	-	37,167	57,361
Unrestricted funds (Note 11)	B19	178,458	-	-	178,458	182,012
Revaluation reserve	B20	-	-	-	-	-
Total funds	B21	178,458	37,167	-	215,625	239,373

Signed by two trustees on behalf of all the trustees

Signature	Print Name	Date of approval dd/mm/yyyy
	Humphrey Hodgson	16/9/2024
	Geoff Holroyd	

Notes to the Financial Statements

1. Basis of Preparation

The financial statements have been prepared on a going concern basis under the historical cost convention.

The financial statements have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). The Charity is a public benefit entity for the purposes of FRS 102 and therefore the Charity also prepares its financial statements in accordance with the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (The FRS 102 Charities SORP) and the Charities Act 2011.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest pound.

Going concern

At the time of approving the accounts, the trustees have a reasonable expectation that the charitable company has adequate resources to continue in operational existence for the foreseeable future. Thus the directors continue to adopt the going concern basis of accounting in preparing the accounts.

2. Accounting Policies

Income Recognition

Income is recognised when there is entitlement to the funds, the receipt is probable and the amount can be measured reliably. Income is recognised in the year to which it relates and on an accruals basis. Legacies are included when the legacy is received or when the charity is notified of an impending distribution which can be quantified and receipt is probable, whichever is the earlier. Recoverable taxation is accounted for on an accruals basis.

Expenditure

Expenditure is accounted for on an accruals basis and allocated directly to the expenditure headings as far as practically possible to reflect the activities of the charity. Charitable activities comprise direct expenditure including direct staff costs attributable to the activity.

Employee benefits – Pensions

The Company operates a defined contribution plan for its employees. These contributions are recognised as an expense when they are due. Amounts not paid are shown in accruals in the balance sheet.

Fund Accounting

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by the donor or are raised by the charity for specific restricted purposes.

Unrestricted funds are funds which are available for use at the discretion of the trustees in furtherance of the general objects of the charity.

The legacies fund is to enable the trustees to manage large legacies in an efficient and effective manner avoiding the financial distortions and instabilities which can be created by the irregular and unexpected receipt of significant legacies.

Cash and cash equivalents

Cash and cash equivalents include cash in hand and bank deposits.

Critical accounting estimates and areas of judgement

In the view of the trustees in applying the accounting policies adopted, no judgements were required that have a significant effect on the amounts recognised in the financial statements nor do any estimates or assumptions made carry a significant risk of material adjustment in the next financial year.

3. Donations and legacies

	Year to 31 Mar 24	Year to 31 Mar 23
	£	£
Membership fees	23,741	21,280
Donations	39,696	32,730
Gift Aid	7,937	5,947
	71,374	59,957
Legacies	14,513	-
	85,887	59,957

Membership fees and general donations have increased by almost 20% year on year.

4. Charitable Expenditure

	Year to 31 Mar 24	Year to 31 Mar 23
	£	£
Staff costs	76,047	62,130
Funding of research project	9,702	-
Other costs	21,540	22,183
	107,289	84,313

5. Trustees

None of the trustees received any remuneration during the year. There were trustee expenses of £125 during the year (nil in 2022/23).

6. Employees

The average number of employees on a full time equivalent basis was 3.1 (2022/23: 2.5).

7. Debtors

	Year to 31 Mar 24	Year to 31 Mar 23
	£	£
PMR Paradox project with Leeds University	17,330	-
PMR Exercise Booklet with Keele University	299	-
Gift Aid accrual	7,500	6,000
Investment Interest	4,200	2,283
	29,329	8,283

8. Creditors: Amounts falling due within one year

	Year to 31 Mar 24	Year to 31 Mar 23
	£	£
Independent Examiner's fee	750	700
Social security and pensions costs	372	266
Other creditors	2,527	1,956
	3,649	2,922

9. Restricted Funds

Restricted Income				
2023/24	Balance at	Income	Expenditure	Balance at
	01 Apr 23			31 Mar 24
	£	£	£	£
Stone King Legacy	18,686	-	-	18,686
James Tudor	100	-	-	-
Anonymous Grantor	1,575	-	-	700
Wellcome Trust	5,981	-	-	5,981
Kent Community Foundation	5,437	-	-	-
Sussex Community Foundation	2,680	-	-	-
Sevenoaks Distric Council	1,400	-	-	-
Member Donation	11,502	-	-	1,800
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	57,361	-	-	37,167
Restricted Income				
2022/23	Balance at	Income	Expenditure	Balance at
	01 Apr 22			31 Mar 23
	£	£	£	£
Stone King Legacy	21,186	-	-	18,686
James Tudor	-	1,500	-	100
Anonymous Grantor	-	1,575	-	1,575
Garfield Weston	1,029	-	-	-
Wellcome Trust	5,981	-	-	5,981
Kent Community Foundation	5,025	4,857	-	5,437
SussexCommunity Foundation	4,726	-	-	2,680
Tesco	510	-	-	-
Sevenoaks Distric Council	-	1,400	-	1,400
Member Donation	11,502	-	-	11,502
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	59,959	9,332	-	57,361
Purpose of each Fund				
Stone King Legacy	To be spent on new development			
James Tudor Foundation	To fund the training and support for the member helpline			
Anonymous Grantor	To fund the training and support for the member helpline			
Garfield Weston	Information packs, marketing and PR			
Wellcome Trust	Roadshows outside London			
Kent Community Foundation	To fund a part-time co-ordinator of the Kent support groups			
Sussex Community Foundation	To fund a part-time co-ordinator of the Sussex support groups			
Tesco	To fund a part-time co-ordinator of the Kent support groups			
Sevenoaks Distric Council	To fund a part-time co-ordinator of the Kent support groups			
Member Donation	Funding for a research project			
Amalgamation with North East PMRGCA	To fund GP awareness of PMR and GCA in the North East			

10. Legacies Reserve

	Year to	Year to
	31 Mar 24	31 Mar 23
	£	£
Opening Balance	112,699	128,799
Additions in year	6,513	-
Transferred to General Reserve	- 14,088	- 16,100
Closing Balance	105,124	112,699

The Legacies Reserve was established in 2020/21 following the receipt of a large legacy in relation to the size of the existing reserves. The amounts transferred to reserves are in accordance with the policy established when the reserve was created.

11. Reserves Summary

	Year to	Year to
	31 Mar 24	31 Mar 23
	£	£
Restricted Income	37,167	57,361
Legacies Reserve	105,124	112,699
General Reserve	73,334	69,313
Total Reserves	215,625	239,373

12. Related party transactions

There were no related party transactions during the year.

ACKNOWLEDGEMENTS

The charity depends on the generosity and support of volunteers. We acknowledge and thank wholeheartedly all those who make the work of the charity possible. We are also extremely grateful to the people who have given their time and effort to raise funds for the charity and to all who have made donations or attended our events.

PMRGCAuk is a small charity with limited resources. Many of those seeking information and support from us do not realise that we are a very small team working remotely. We work hard to spend every penny of our fund wisely.

Appendix 1

Reference and administrative details of the charity

Name of Charity: Polymyalgia Rheumatica and Giant Cell Arteritis UK (PMRGCAuk) Charity

Registration No: 1128723

Company Registration No: 6763889

Registered Address: 10 Coldbath Square, London, EC1R 5HL

Office/Correspondence Address: BM PMRGCAuk, London, WC1N 3XX

Bank Details: HSBC, 13 Parliament Street, York

Trustee/Directors: Humphrey Hodgson (Chair), Janice Maddock (Deputy Chair), Geoff Holroyd (Treasurer), Penny Denby (until September 2023), Dr Vanessa Quick, Sara Muller (until February 2024), Christine Young (until September 2023), Wendy Morrison, Fiona Johnson, Gail Booth and Bill Mansfield.

Independent Examiner: Katherine Gamage from Gamage Accountancy

President: Professor Bhaskar Dasgupta

Patrons: Lord Robin Butler, Lady Wendy Levene, Dr Sarah Mackie, Dorothy Byrne

Staff: Candy Horsbrugh (Director until September 2023), Sophie Boyce (Director from August 2023), Fran Benson (Membership Secretary & Assistant Director), Neelam Russell (Kent Regional Organiser until March 2024 and National Support Group Manager until September 2023), Charon Balarabe (Administrative Assistant) and Lucas Coutin (Northern Outreach Lead).

About the charity

PMRGCAuk is the national charity for those with Polymyalgia Rheumatica and Giant Cell Arteritis. We were formed in 2008 by the 'PMR Fighters', a group of patients who came together determined to find out more about these little-known conditions and create a national network of support so that no one need face these diseases alone.

With the support of many wonderful volunteers, PMRGCAuk now supports over 3000 people a year through our national network of support groups, our telephone helpline, and our online forum. We have become a go-to source of information through our website. Reaching out to the medical research community, we have been instrumental in helping to shape and perform research, have lobbied for new treatments, and raised awareness on the front line of diagnosis – the GP surgery.

We campaign to raise awareness amongst the general public and healthcare professionals so the correct diagnosis and treatment can be rapidly reached by GPs and other healthcare professionals.

With an urgent need for support and information, the charity was set up over 10 years ago by a patient group – 'The PMR fighters' – and remains governed today by Trustees the majority of whom live with one of the conditions, as well as being shaped by a membership of patients with either PMR or GCA. The charity ensures those diagnosed never need feel alone or unsupported. Empowered with information, those living with the conditions are better able to have informed discussions with their doctors and health professionals and feel more in control of their destiny.

The charity's objects are:

- a) To advance the education of the public through the collection, assimilation and recording of information and data relating to polymyalgia rheumatica and giant cell arteritis by the provision, establishment and maintenance of an educational website, and a network of support groups.
- b) To preserve and protect good health by the promotion of research into polymyalgia rheumatica and giant cell arteritis and the dissemination of the useful results thereof for the benefit of the public.

The charity's activities

We provide information and support to people with PMR and GCA

- Support a national network of support groups.
- Provide a telephone helpline run by volunteers with experience of the conditions.
- Maintain an online forum for peer support.
- Produce a free information pack to people newly diagnosed with PMR and GCA
- Organise an annual members' day with guest speakers and facilitated discussions.
- Publish a members' magazine three times per year & send regular email and letter updates.
- Maintain and up to date website and improved social media.
- Distribute information to rheumatology departments and other relevant locations. We raise awareness within the public domain, medical profession and government.
- Conduct national press and media work to increase public awareness.
- Speak to groups of people over 50 and those who work with them.
- Attend meetings with health professionals and NHS England.
- Advocate for fast and effective diagnosis and treatment to prevent sight loss resulting from undiagnosed GCA.
- We support and promote research into PMR and GCA.
- Provide patient representation on international working groups, such as those to develop new guidelines for the management of PMR and GCA.
- Become actively involved in research projects undertaken by other organisations, primarily through patient representation.

For a small charity, we are proud of our impact, helping thousands of individuals each year through the services we provide, online, on the telephone and through our national network of support groups. Our work supporting the medical and research community through vital patient representation has also helped to drive change in diagnosis and treatment including the release of new international clinical guidelines for GCA, released in January 2020, developed to standardise diagnosis and treatment around the world.

Since forming, demand for the services of the charity has grown considerably and we are now supporting over 5,000+ people a year through our various services, run by a small core staff team supporting a network of over 50 volunteers. The need for our work is clear to us, highlighted by our growth in membership; the growth of our national network of support groups and the increase in those accessing our information, as well as a wealth of positive stories from those using our services.

Appendix 2

Part A – Report from support groups

Not all groups choose to provide a report.

Dorset: We are a new group which started in March 2024 covering the Dorset area. We are growing slowly, with new people arriving each month. The overwhelming feeling for new members seems to be relief at realising they are not alone and isolated. This rare disease is little understood. Over the next few months we will be welcoming Dr M Khurshid Consultant Rheumatologist from Poole Hospital who fully supports our group. We are planning to invite other specialists from the Osteoporosis Society, a dietitian, and will be investigating alternative ways of dealing with fatigue and sleep problems.

Havant: The Havant (Portsmouth) support group has been up and running since May 2023 and our membership is now at 37, although not all members attend at once! We have been superbly supported by the Rheumatology Team of our local hospital. Their senior nurse has been providing question and answer sessions and arranging visits from a wide range of speakers on a variety of topics related to PMR and GCA. These include nutrition, graded exercise, bone health and sleep. Two of the rheumatology consultants have also delivered sessions on current medical research and steroids and the adrenal glands. We are extremely grateful for the continued active support from the Rheumatology Team.

Brighton: The Brighton group is a small but very supportive group who meet face to face with a Zoom option. We regularly have new members who find the information from fellow PMRGCA sufferers really helpful, especially in answering their questions. Equally we are very happy when members leave because they no longer need us because they are now better.

Plymouth: Plymouth Group had several meetups during the year, with little activity during mid-winter and mid-summer months. We met at the Discovery Café on selected Tuesday mornings at 11am. The café adjoins the Central Methodist Hall in Eastlake Street, Plymouth – well-placed for city centre shopping and lunches available. We're open for suggestions and would like to get a speaker at some stage, and perhaps join with a neighbouring group on occasions.

Cumbria: The group is now well established in the sense of regular meetings (approx. every 6 – 8 weeks) held in various café venues across the county but settling now mainly in Kendal and Sedburgh. They are a café and chat style of exchange of information and support. Attendance varies from three to eight. There is a mix of men and women and ages range from 50s to 80s. Not everyone comes to every meeting – it's a drop in arrangement to suit individuals. Mostly it's about PMR but a few have GCA and one or two people have both. Most of our members now find out about the group online e.g. via the charity's website though we have had one referral via a GP. People come from a wide area e.g. Carlisle, Richmond, Morecambe. Many are interested because they have been newly diagnosed and want to learn more about the condition. The main topics are about symptoms, GP/specialist diagnosis, steroid tapering, approaches to managing the illness and increasingly long-term effects of the condition and medications. Experiences vary from very good support by health care professionals to poor monitoring and feelings of abandonment by medics. We hope to continue in the coming year along similar lines and always aim to offer support and welcome to anyone who attends.

Isle of Wight: The Isle of Wight support group started on May 8th with 11 people present. We all agreed we would like the group to continue, and we realised that considering we all live under one healthcare system everybody's experiences have been very different. We have a range of

experiences, people who have had PMR/GCA for eight or nine years, people who have only been diagnosed in the last couple of months and everyone in between. What has been great is being able to share experiences of medication for people who may be about to experience it. We meet the first Wednesday evening of the month, we have plans for a consultant rheumatologist, a dietician and an ophthalmologist to come and speak with the group.

Whitstable: Whitstable has become such a great support group – our attendance ranges from seven to 17 at the meetings. The group made a unanimous decision last year to hire a private room each month. We are very lucky with our venue as there are many available, all with Wi-Fi. This gives us more privacy and has made a significant difference to our discussions, just last month we had a recording on *Mood and Wellbeing with Steroids* which really opened up a topic we have not really covered before. We often have a seated exercise session and every month there is always *Chat Round the Room* where everyone joins in and benefits. Back in March we watched the recording based on our new exercise booklet – a great meeting ably supported by Neelam who we bade farewell to and presented her with something for her garden. We've been able to distribute 20 of the booklets and have sent a donation to HO for them. We are hoping for more guest speakers and, if all that fails, we will run a quiz! One of our members has offered to set up a WhatsApp group to help us stay in touch. What is so good is that we always end up having a laugh about something, such good medicine.

Maidstone: Maidstone support group has continued to meet monthly, welcoming quite a few new people to our social group this year. Meetings are fairly informal, sharing experiences and offering mutual support. We have discussed a range of different topics relevant for patients, using information and resources from the PMRGCAuk website, and from other professional charities. In July 2023, we enjoyed a home fire safety talk from Kent Fire and Rescue Service, and in the spring we looked at the charity's new exercise booklet, following its launch in January 2024. Members have also participated in some of the webinars which have been organised by the charity throughout the year, as well as the regular online support group.

Yorkshire: This year saw our return to John Lewis Community Hub in Leeds on 12th June. Until then we did not have anyone who was able to lead the meeting. It was not as well attended as before and only four people came. We have not given up yet as I am sure there are a lot of people in Leeds with PMR/GCA who would benefit from the support group. We will try a few more times to see if the venue and location are the issue or there are other reasons people cannot attend. Yorkshire is a large area to cover; we support four locations: Ilkley, Leeds, Sheffield and York. This year we have held 10 meetings and 10 Zoom sessions. The group was founded in Ilkley in the summer of 2017 by two members who met at the charity's research roadshow in Leeds in March of that year. It grew to cover more of Yorkshire for people in outlying areas. We also have Zoom sessions for those who can't travel. Anyone is welcome to attend regardless of postcode. The mindfulness session this year on Zoom was well attended and enjoyed by all those who joined in. There is an average of six to 10 people who attend Ilkley and York. We have about 4-6 who come to Sheffield. The meetings are informal, held in a café or community room. The aim is to provide a less structured approach for the group to put them at ease, enabling conversation and a question-and-answer session. The Northern Outreach Lead, appointed in October, is based in Leeds and will help broaden our appeal to reach more people. We continue to forge ties with local rheumatologists at Leeds Teaching Hospital, getting involved in research programmes and benefiting from their webinars. We look forward to working together in the future. The group has a good sense of community and provide support for each other in many ways that might not be PMRGCA related. They share ideas on crafts, hobbies, health issues and other interests which is a good way to take your mind off the daily struggle of living with PMR or GCA and the effects of steroid use.

Luton & St Albans: Our group was formed following a patient event held in December 2022 by Dr Quick at the Luton and Dunstable Hospital. We first met as a support group at 11.00 on Wednesday 1st February 2023 at The Rose Garden Cafe at the Hertfordshire Garden Centre in Redbourn and six people attended. It was agreed that our first venue was quite small therefore we looked for a venue that could accommodate a larger group so our second meeting was held at The Stockwood Park Discovery Centre Cafe in Luton. This venue proved popular and we then met every three months here. Following two newly diagnosed members joining us, the group decided it may be beneficial to meet more frequently and since May 15th of this year we have met every two months. We now have 12 people on our mailing list.

Sevenoaks, Tonbridge & Tunbridge Wells: We meet in the usual rhythm (every two months) but are currently looking for a new meeting place.

Chichester: Our group of usually 8–10 people is going very well and everyone says what a success and help our monthly meetings are to them. Even though we all have PMR/GCA (with the exception of Val our tea lady who still attends although it was her late husband who had the condition) we all find so much to laugh about and humorous stories to tell that everyone enjoys and looks forward to our meetings. They all go away with a smile on their face which is a pleasure to see.

Worthing: The group is growing slowly – we get a steady trickle of new members almost balanced out by members leaving because they're finally off steroids and in remission, which is good news for all of us, proving it can be done. It's a pretty sociable group too: we held a Christmas party which went so well that we're holding a tea party in the summer.

Cheshire: The Cheshire group was established in September 2023 when one of our new members found the nearest support groups were in Shropshire, Cumbria or Yorkshire. It is a relatively small but growing and thriving group, attracting members from as far apart as Oldham, The Wirral, Derbyshire, Stoke and of course Cheshire. New members are always welcome. Due to this diversity the group alternatives its meetings between face-to-face meetings and online. The group is informal and provides, friendship, shared experiences and support. It is a privilege to lead this group. I've met a wonderful, interesting group of people and feel like it really makes a difference. One new member sent me a message after her first meeting 'I just want to let you know how important that meet up was for me and thank you again for arranging. Listening to R and getting the book H recommended encouraged me to act on my symptoms and I just had an ultrasound which confirmed GCA.' Feedback like this makes it worthwhile and demonstrates the power of group meetings.

Barnet: After a break of several years – last meeting February 2020 – we restarted this year with a meeting in March 2024. Seven attended and everyone had a chance to tell their story. A final few minutes of general discussion always produces fresh ideas which the group can add to their own knowledge of PMR – pill splitters, web sites and experiences with fast and slow reductions to name a few.

Orpington: In 2012, following a meet up organised through HealthUnlocked I met with two people from Kent in a Dunelm Mills coffee shop. Eight HU members then met for lunch in a pub at Chelsfield. We have moved over the years from a church hall in Chelsfield, my house, a room at Community Links in Bromley, a local pub and then we settled at St Paul's Church where we have been meeting now for at least six years.

Welwyn Garden City: I live in Welwyn Garden City and after being diagnosed with PMR in 2017 and subsequently GCA in 2018, I thought it was time I started a support group in my area as the nearest one was too far for me to travel at the time. The PMRGCAuk website had been especially useful in

helping me find out as much as I could about the conditions, so I contacted them about starting a support group. The Welwyn Garden City support group's first meeting took place on 5 September 2019 when Janice Maddock, Trustee, kindly joined us to explain the work of PMRGCAuk. The face-to-face bi-monthly meetings continued in a hired local church hall until March 2020 when it became apparent that these meetings were no longer feasible as Covid began to take its toll on the population, so we reverted to monthly Zoom meetings. I originally recorded 15 members, but many of those decided they either could not manage Zoom, or it just was not convenient, even though I offered to help them get to grips with the technology. The group subsequently dwindled but we continue to hold the Zoom meetings for a select few who cannot, for various reasons, travel far or leave home. The offer still stands for anyone in another part of the country to join in these sessions if they do not have the facility locally. The membership has gradually grown again, and there was a consensus for face-to-face meetings to start up again. In November 2023 I chose a more central venue in a café on the first floor of the local cultural centre in Welwyn Garden City where there is a lift and an adjacent car park. We can sit separately from other members of the public quite comfortably, purchase something to drink or eat and chat about anything that can help members understand the various issues that arise from PMR or GCA. The common themes are the difficulty with tapering prednisolone and the paucity of GP or consultant appointments. We have had a steady year to date. The dates of the meetings are confirmed in advance on the local support groups' page of the PMRGCAuk web site in case there are any changes.

Pinner and Ruislip: The Pinner and Ruislip Group continues to support a steady number (approx 60 +) of people with PMR and GCA both online and face to face. The group has had a good year with a few speakers and the added benefit of Wendy Caines joining Janice as joint Group Organiser.

Part B – Report from PMR-GCA Scotland

SCOTLAND REPORT FOR UK CHARITY'S ACCOUNTS 2024

2023 saw us return to normal activity after an extended period when we seemed to be wholly at the mercy of Covid-19. Our support groups have revived regular meetings and they all have a full schedule in place for 2024. Membership stands at 331 members which is a satisfying increase from 311 last year.

Supporting people affected by PMR and GCA is a primary aim of the charity and this is best done through personal contact. We achieve this through our support groups and the helpline which both involve listening to problems, discussing them, and offering advice and reassurance where appropriate. We cannot give medical advice but the breadth of experience which can be tapped into can often help patients to engage more fully with their health professionals. The website is another fulltime support that we offer and even it has a personal touch. The sections with medical information, patients' stories and the FAQ section all have a distinctly personal feel which makes them very usable. Our other personal interaction with members is through our AGM which is held online.

The other main objective of the charity is to support and promote treatment and research activities into PMR and GCA. This is done in a variety of ways including participation in committees and organisations involved with delivery of health services (governmental and non-governmental) and also participation in committees and projects involving themselves with research of various types. A list of such activities gives a flavour of these involvements, but doesn't fully convey the time and effort which is expended on behalf of the charity. In this regard I must make specific mention of Lorna Neill who accounts for almost all of this work. She does enormous amounts for the benefit of patients worldwide and is unstinting in sharing her knowledge with our own membership. We had hoped to revive our practice of offering financial support to projects that meet our objectives but with no reportable outcome at this time – we will continue to pursue this aim.

About half of our members maintain contact with one of our local support groups. We have five groups operating currently which meet regularly in Aberdeen, Dundee, Glasgow, Edinburgh, and Inverness. For some members it is just not possible to attend meetings whether that be due to geography, employment, health issues or child-care commitments. Our online Zoom meetings have allowed some participation for such members and we plan to continue this activity on a more regular basis in the future.

All the work mentioned in this report would not be possible without the efforts of all our members to some degree or other. I must, however, give special thanks to our trustees, to our helpline volunteers, and to the organisers of our support groups. The trustees are extremely grateful to all those individuals and trusts who support the charity financially.