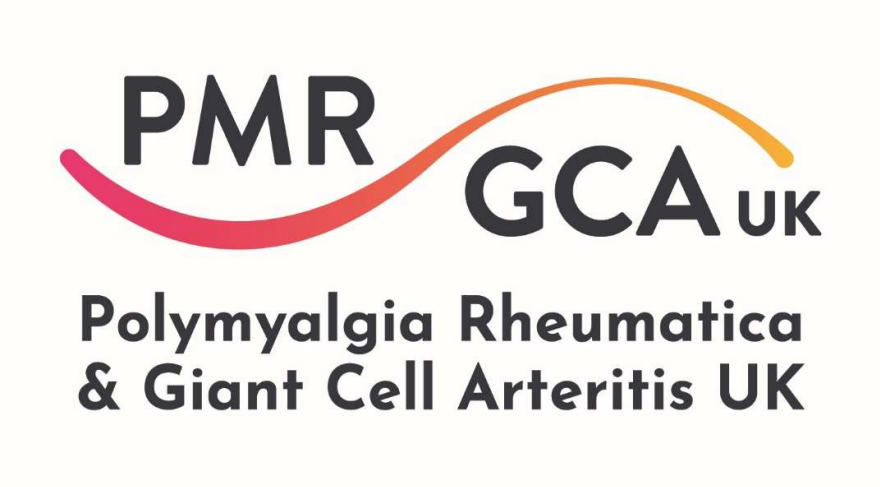

Accounts

and

Annual Report

2024-2025

Message from Chair of Trustees

The core activities of the Charity are supporting people with PMR and GCA, raising awareness, lobbying for improved services, and research. I think we can congratulate ourselves on continued activity in all these areas – thanks to our members, our volunteers, our partners and our staff.

As this report shows, our support systems thrive with a number of new support groups being formed, importantly some in the north of England, although we still remain 'bottom-heavy' in the south and west. Our helpline is in continuous demand, and we interact with over 4000 people via Health Unlocked; we owe a huge debt to those who man the telephones and who oversee the on-line conversations.

Our website is continually updated, and allows access to our series of webinars, which we know are hugely appreciated. Some topics unfortunately never tire, such as the problems of prednisolone therapy, but we are delighted to have been asked to contribute to the NICE (National Institute of Health Care Excellence) review of a new therapy for GCA. We have also engaged with the NHS England's 'Musculoskeletal Czar', though we worry that subsequent decisions to dismantle that organisation may make national efforts to improve services more difficult to achieve. Our 'Freedom of Information' request to the Department of Health yielded important information on the patchiness of rapid diagnostic facilities for GCA.

In research, together with Sarah Mackie in Leeds (one of our patrons and a huge supporter) this year saw the end of the information-gathering phase of the research project funded by NIHR (the National Institute of Health Services Research) on the PMR paradox, investigating why PMR is less frequently recognised in the North of England. Next year should see the results published. Importantly we have also established ourselves as the go-to for consultation when academic researchers apply for grant funding in PMR and GCA.

Kate Gilbert, one of our founders, has agreed to update – it will be the third edition – her much appreciated book on Living with PMR.

Finally we could not have achieved one tenth of this without our staff. Our new director Sophie Boyce settled in rapidly and has been extremely effective; and Fran Benson not only creates Newswire, but made a huge contribution by initiating the 'marathon in a Month' fundraising campaign, which has succeeded not only financially but also by creating new friendships and interactions. Personally I cannot thank them, and our administrator Charon Baralabe, enough.

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 took the decision to raise our membership fee in October 2024, from £15 to £22. It had been a number of years since we last raised our fee, in which time costs have risen steeply. We are very appreciative of everyone that has supported us in this increase.

By the end of March 2025 we had 1800 members. This includes patient, friend and professional members.

Members' Day

Our 2024 Members' Day and AGM took place online again. Our speakers this year were Dr Christian Selinger and Professor Emma Clark.

Dr Christian Selinger spoke about the case for and against stomach protection while on prednisolone. His talk covered proton pump inhibitors such as omeprazole and lansoprazole, why they might be used, their benefits and the potential risks.

Professor Emma Clark then spoke about the case for and against bone protection while on prednisolone. Her talk covered the risk factors for broken bones, including having a diagnosis of PMR or GCA, being on steroids, inflammation, and age, and how bisphosphonates, calcium and vitamin D can help to reduce the risk of breaking a bone.

Both talks were extremely well received and our thanks to Vanessa Quick for compering the talks.

PMRGCAuk Week 2024

We hosted two professional webinars for PMRGCAuk week in June 2024, and also presented a charity spotlight webinar. We had more than 320 members and guests to our PMRGCAuk week webinars.

Consultant Physiotherapist Will Gregory launched our inaugural Marathon in a Month with his webinar about improving outcomes through exercise and activity. He spoke about the role of a physiotherapist, as well as the different benefits of exercise and how to maximise these.

Dr Sarah Mackie talked about the hidden complexities of PMR and GCA and talked through five approaches people can take to help themselves through.

The charity spotlight, hosted by Director Sophie Boyce, was an opportunity for staff and trustees to talk about the different areas of work the charity is involved with, and the different ways we provide support.

Thank you to all our members who got involved with fundraising and awareness raising efforts during PMRGCAuk week.

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 currently working consists of four volunteers Stephanie Beer, 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. During the past year Trish Galli has retired from working on the helpline and Monica Alderton is currently having a break. This means that the remaining four volunteers are having to do significantly more shifts on the helpline and there is an urgent need for some new volunteers to enable the helpline to keep running.

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

The Helpline volunteers spoke to 384 callers from April 2024 to March 2025 an increase of 30 from last year, with slightly fewer calls received in December and February than the rest of the year.

Statistics

- 70% of callers had PMR; 20% GCA; and 10% had both. This is a very similar spread to 2022/2023.
- The average age of callers was 72 years old last year the average age of callers was 76.
- 81% of callers were female; 19% male this is a decrease of 5% from last year.
- 58% of callers were newly or recently diagnosed; 39% had been diagnosed between 1-4 years and 8% had been diagnosed over 5 years. 3% of callers did not disclose how long they had been diagnosed or were calling on behalf of someone else. This is a significant increase in newly diagnosed patients calling the helpline which may reflect health practitioners having insufficient time to talk to newly diagnosed patients.
- 65% of people we spoke to were first time callers, and 33% of all callers had called more than once (2% did not say). This is like last year.
- 90% 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 8% about steroid sparing drugs.

- 73% 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 58% last year.
- 14% of callers shared that they felt unhappy, dissatisfied or angry before calling a reduction of 3% from last year.

25% of callers are recorded as being members of PMRGCAuk, a decrease from 28% in 2023/2024.

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.

The majority of our groups meet face to face in public settings, such as coffee shops and community rooms, with some hiring a dedicated space for each of their meetings. We also have a growing number of online groups. Penny Denby's dedicated online group has been joined by online groups run by a number of our regional GOs. These groups welcome those from outside of their areas who would otherwise find it hard to attend a meeting.

We continue to update our website with details of each group's next meeting and support GOs to advertise their groups locally. Charon Balarabe has been supporting the group organisers this year, making sure posters are sent out and details updated on the website. We hold regular meeting for our group organisers to attend, which gives everyone a chance to share how things are going, troubleshoot challenging situations, and keep up to date with charity news.

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. We share regular group news in NewsWire, which is published three times a year, and we try to feature a different group organiser in every edition to share how all of our groups work.

PMRGCAuk Information Packs

Our information packs continue to be a popular resource, with the total number of packs requested in 2024-2025 representing a 9% increase on 2024-2024'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

2024/2025
Total information packs requested: 1731
Hard copy: 425
Digital copy: 1306

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 2025, we had 4601 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.

In March 2025, there were 352 posts (threads) made on the forum, inviting a total of 6205 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.

MARATHON IN A MONTH

In July 2024 we introduced a new campaign called Marathon in a Month. As well as being a great fundraising and awareness spreading opportunity, it also saw our members benefit from increased exercise and activity and, for those that took part in groups, allowed them to build and grow friendships with other members.

The event raised a phenomenal £11,000 for the charity and we received so much positive feedback on the benefits members felt from taking part.

Research and awareness

In May 2024, we were invited to the launch of Charity President Professor Bhaskar Dasgupta and Dr Christian Dejaco's study meeting, The GCA-PMR Spectrum; Moving on After 65 years. The day was primarily aimed at consultants to consider what is now considered best practice for diagnosis and treatment of PMR, GCA and LVV, but charity members were also invited to attend the event to share their viewpoints and experiences.

Since the meeting, Professor Dasgupta and others have gone on to carry out a DELPHI study on their proposals to reach a consensus on how these conditions should be approached going forward.

March 2025 saw the completion of our research project The Polymyalgia Paradox: Addressing north-south inequities in polymyalgia rheumatica using grassroots community connectors in a deprived urban area. The project involved Dr Sarah Mackie from University of Leeds, Dr Sarah Muller from Keele University, Dr Hanif Ismail from Leeds Teaching Hospitals NHS Trust, wider colleagues at all three institutes, and Lucas Coutin who was employed as the charity's Northern Outreach Lead for the Project.

The project aimed to identify barriers to diagnosis, care and support faced by people with PMR from under-served communities and create a roadmap for overcoming these barriers.

One of the key outputs from the project was the videos Lucas created with our members, sharing their varied experiences with PMR and GCA through diagnosis, treatment and recovery. These have already been used to aid clinician education and awareness raising and give a rich insight into people's experiences with these conditions.

The full report on the project, covering the methods used, key findings, outputs and dissemination, conclusions and future plans will be made public and shared with charity members once the final document has been signed off with the NIHR.

Lucas's role with the charity came to an end in line with the completion of the project and since leaving the charity he has moved to Denmark where he will be studying for his Masters degree in Nordic Town Planning.

PMRGCA

Annual Report and Accounts for 2024/25

Financial Review

This year we recorded a surplus on all activities of £6,620 which is an improvement over last year which saw a deficit of £23,748.

Income

Income for the year was £143,688, a 23% increase over last year's total of £116,645. Our main source of income is the subscriptions and donations of the charity's members and supporters which totalled £93,532, an increase of 27% over the previous year.

We received £4,085 as the final instalment of a legacy, £35,005 from the PMR Paradox project with Leeds University, £9,030 of interest on the investment of our surplus funds and £2,036 from other activities.

Expenditure

Expenditure for the year was £137,068 of which the major cost was salaries totalling £108,468. The only expenditure on restricted funds was £700 for the helpline volunteer training programme.

Balance Sheet

As a result of the surplus for the year total funds increased to £222,245. 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 £9,055, Restricted Reserves increased by £1,085 and the General Reserve increased by £14,590 to £85,582 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. Restricted Reserves

During the year the policy of allocating a proportion of the interest earned on surplus funds to restricted funds was introduced. This was applied retrospectively to the years 2022/23 and 2023/24. Prior to 2022/23 the amounts of interest earned were immaterial.

3. 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.

CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	Charity Name Polymyalgia Rheumatica and Giant Cell Arteritis UK		
On accounts for the year ended	31 March 2025	**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 31/03/2025.

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 (other than that disclosed below *) 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:	Th 6	**Date:**	6th August 2025
Name:	Katherine Gamage ACMA		
Relevant professional qualification(s) or body (if any):	Associate Member of the Chartered Institute of Management Accountants (ACMA, CGMA).		
Address:	8 Pemscott Close Alvescot Oxfordshire, OX18 2QE		

Section B Disclosure

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	01/04/2024	To	Period end date	31/03/2025	

Section A Statement of financial activities (including summary income and expenditure account)

Recommended categories by activity	Guidance Notes	Unrestricted funds £	Restricted income funds £	Endowment funds £	Total funds £	Prior year funds £
Incoming resources (Note 3)		F01	F02	F03	F04	F05
Income and endowments from:						
Donations and legacies	S01	97,617	-	-	97,617	85,887
Charitable activities	S02	36,532	-	-	36,532	21,847
Other trading activities	S03	509	-	-	509	799
Investments	S04	7,245	1,785		9,030	8,112
Separate material item of income	S05	-	-	-	-	-
Other	S06		-	-	-	-
Total	S07	141,903	1,785	-	143,688	116,645
Resources expended (Note 4)						
Expenditure on:						
Raising funds	S08	35,113	-	-	35,113	27,862
Charitable activities	S09	97,419	700	-	98,119	97,587
Separate material item of expense	S10	-	-	-	-	9,702
Other	S11	3,836	-	-	3,836	5,242
Total	S12	136,368	700	-	137,068	140,393
Net income/(expenditure) before tax for the reporting period	S13	5,535	1,085	-	6,620	- 23,748
Tax payable	S14	-	-	-	-	-
Net income/(expenditure) after tax before investment gains/(losses)	S15	5,535	1,085	-	6,620	- 23,748
Net gains/(losses) on investments	S16	-	-	-	-	-
Net income/(expenditure)	S17	5,535	1,085	-	6,620	- 23,748
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	5,535	1,085	-	6,620	- 23,748
Reconciliation of funds:						
Total funds brought forward	S23	176,116	39,509	-	215,625	239,373
Total funds carried forward	S24	181,651	40,594	-	222,245	215,625

Balance Sheet

		Charity Name PMRGCAuk		Charity No	1128723
				Company No	6763889

Section B Balance sheet

	Guidance Notes	Unrestricted funds £	Restricted income funds £	Endowment funds £	Total this year £	Total last year £
Fixed assets		F01	F02	F03	F04	F05
Intangible assets	B01	-	-	-	-	-
Tangible assets	B02	-	-	-	-	-
Heritage assets	B03	-	-	-	-	-
Investments	B04	-	-	-	-	-
Total fixed assets	B05	-	-	-	-	-
Current assets						
Stocks	B06	-	-	-	-	-
Debtors (Note 7)	B07	20,895	-	-	20,895	29,329
Investments	B08	143,462	32,060	-	175,522	166,779
Cash at bank and in hand	B09	19,197	8,534	-	27,731	23,166
Total current assets	B10	183,554	40,594	-	224,148	219,274
Creditors: amounts falling due within one year (Note 8)	B11	1,903	-	-	1,903	3,649
Net current assets/(liabilities)	B12	181,651	40,594	-	222,245	215,625
Total assets less current liabilities	B13	181,651	40,594	-	222,245	215,625
Creditors: amounts falling due after one year	B14	-	-	-	-	-
Provisions for liabilities	B15	-	-	-	-	-
Total net assets or liabilities	B16	181,651	40,594	-	222,245	215,625
Funds of the Charity						
Endowment funds	B17	-			-	-
Restricted income funds (Note 9)	B18		40,594		40,594	39,509
Unrestricted funds (Note 11)	B19	181,651		-	181,651	176,116
Revaluation reserve	B20				-	
Total funds	B21	181,651	40,594	-	222,245	215,625

Signed by two trustees on behalf of all the trustees	Signature	Print Name	Date of approval dd/mm/yyyy
		Fiona Johnson	
		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 the 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 25	Year to 31 Mar 24
	£	£
Membership fees	30,934	23,741
Donations	54,620	42,103
Gift Aid	7,978	7,937
	93,532	73,781
Legacies	4,085	14,513
	97,617	88,294

Membership fees and general donations have increased by 27% year on year.

4. Charitable Expenditure

	Year to 31 Mar 25	Year to 31 Mar 24
	£	£
Staff costs	78,939	76,047
Funding of research project	-	9,702
Other costs	19,181	21,540
	98,119	107,289

5. Trustees

None of the trustees received any remuneration during the year. There were no trustee expenses (£125 in 2023/24).

6. Employees

The average number of employees on a full time equivalent basis was 3.3 (2023/24: 3.1).

7. Debtors

	Year to 31 Mar 25	Year to 31 Mar 24
	£	£
PMR Paradox project with Leeds University	8,750	17,330
PMR Exercise Booklet with Keele University	-	299
Prepayments	51	
Gift Aid accrual	8,200	7,500
Investment Interest	3,893	4,200
	20,895	29,329

8. Creditors: Amounts falling due within one year

	Year to 31 Mar 25	Year to 31 Mar 24
	£	£
Independent Examiner's fee	800	750
Social security and pensions costs	293	372
Other creditors	810	2,527
	1,903	3,649

9. Restricted Funds

Prior to 2024/25 investment income had not been allocated to Restricted Income balances.
In these accounts Investment Income has been allocated across all reserves with effect from 01 April 2022, causing an increase in the opening balace for 2023/24 (£58,094) compared with that reported in last years accounts (£57,361).

2024/25	**Balance at 01 Apr 24**	**Income**	**Expenditure**	**Balance at 31 Mar 25**
	£	**£**	**£**	**£**
Stone King Legacy	19,721	907	-	20,628
James Tudor	-	-	-	-
Anonymous Grantor	700	-	- 700	-
Wellcome Trust	6,306	290	-	6,596
Kent Community Foundation	-	-	-	-
Sussex Community Foundation	-	-	-	-
Sevenoaks Distric Council	-	-	-	-
Member Donation	2,239	103	-	2,342
Amalgamation with North East PMRGCA	10,543	485	-	11,028
	39,509	1,785	- 700	40,594

Restricted Income 2023/24	**Balance at 01 Apr 23**	**Income**	**Expenditure**	**Balance at 31 Mar 24**
	£	**£**	**£**	**£**
Stone King Legacy	18,994	727	-	19,721
James Tudor	100	-	- 100	-
Anonymous Grantor	1,575	-	- 875	700
Wellcome Trust	6,073	232	-	6,306
Kent Community Foundation	5,437	-	- 5,437	-
Sussex Community Foundation	2,680	-	- 2,680	-
Sevenoaks Distric Council	1,400	-	- 1,400	-
Member Donation	11,680	261	- 9,702	2,239
Amalgamation with North East PMRGCA	10,155	389	-	10,543
	58,094	1,609	- 20,194	39,509

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
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
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 awareness in the medical professions of PMR and GCA in the North East

10. Legacies Reserve

	Year to 31 Mar 25	Year to 31 Mar 24
	£	£
Opening Balance	105,124	112,699
Additions in year	4,085	6,513
Transferred to General Reserve	- 13,141	- 14,088
Closing Balance	96,069	105,124

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 31 Mar 25	Year to 31 Mar 24
	£	£
Restricted Income	40,594	39,509
Legacies Reserve	96,069	105,124
General Reserve	85,582	70,992
Total Reserves	222,245	215,625

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 virtually. 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, Bill Mansfield and Margaret Bassendine.

Independent Examiner: Katherine Gamage from Gamages 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.

Pamela Noble – East Dorset
The East Dorset group is flourishing with new members joining.
Since splitting with west Dorset we are able to give more time and support to our members which is much appreciated.
Last month we had a useful discussion exchanging information about the different costs of travel insurance.
Several members felt well enough to have taken holidays recently which is to be celebrated.
Sylvie gave a short talk on Well Being.

We are very lucky that our local Consultant Rheumatologist Dr. Khurshid is so supportive of the group and he is attending the next meeting in July. West Dorset are joining us on this occasion.
In future we are hoping to locate a Pharmacist to attend our meeting to help us understand more about specific medications and how they interact.

Once again we are planning to have a Christmas lunch in late November at the Garden Centre.

Christine White
It has been great to welcome along quite a few new members this year, who have joined us for our monthly gatherings in Maidstone, and we've been able to share our many differing experiences. We've discussed everything from steroid tapering, managing fatigue and pacing and the effect of medication on the adrenal glands and the HPA axis, as well as tips about not eating liquorice while taking prednisolone, because it can increase the amount of steroid in your body, and how to add medical information and emergency contact/s to your phone's locked screen.

In May we had a presentation on home fire safety awareness from Kent Fire & Rescue Service, which included details of the free home Safe and Well visits available for customers who may have particular needs or priorities, including living with long term medical conditions. A couple of us were even able to be referred for a home visit there and then!

Joan Mowl & Sue Beesty – Shropshire
The Shropshire group meets regularly in the Community Room in Tesco Extra, Shrewsbury.
Recently we have been able to discuss new research and moves to rename PMR and GCA (and LVV) to GPSD. This is an acronym for Giant Cell Arteritis, Polymyalgia Rheumatica and Large Vessel Vasculitis Spectrum Disease. All of which should be treated as part of a spectrum of the same disease.

We are hoping to arrange special guest speakers or an activity. If you have any suggestions and would like to attend any of our future support group meetings, please email us on shropshire@pmrgca.org.uk.

Janice Maddock & Wendy Caines – Pinner & Ruislip
Both the Pinner and Ruislip groups continue to thrive with a core group of attendees. We had one speaker from Age UK who came and spoke about the services they offer and about benefits that they can help with claiming. Discussions over the last year included issues such as the importance of moving, tapering, adrenal insufficiency, sick day rules and support from GP's (or lack of in some cases) Wendy and Janice enjoyed a lovely Christmas meal with some of our members and we look forward to our first Summer Lunch in July as well as our group effort completing a Marathon in a Month.

Anne Smedley – Whitstable
We had a really lively start to 2025, everyone has something to talk about especially after Xmas.

Our meetings usually attract about 11 members each month & we also encourage people to give their apologies.

February saw us having a seated exercise session & for the first time Health Unlocked was discussed. This opened up a whole new range of topics not discussed before & possibly created some new members!

April had us watching a Zoom recording about our Stomach Protectors - an eye opener for some.

Lou Arnold was our guest speaker in May, we had 13 join her Active Body Active Mind class which focuses on improving balance, strength & coordination. Who knew children's playthings - bean bags, hopscotch (no jumping) & walking a tightrope line would cause so much laughter!

Tessa Tipp & Pauline Kenny – West Dorset
The West Dorset group was formed in March ’25 with attendance from Beaminster/Bridport/Yeovil/Weymouth areas. Numbers attending the East Dorset group had grown too large and journey time is now reduced for some members from 1hr+ to 30 mins each way. As members predominantly suffer from GCA, this move was welcomed. Initially 11 members attended falling to 6 at subsequent meetings, due to holidays and date clashes. It is jointly run by previous East Dorset members to allow continuity when absent.

We meet monthly at the PIP Poundbury café in a separate meeting room at a cost of £10/hr, which initially is being privately funded. This is a lovely venue with big windows, comfortable seating and self-catering coffee/tea available for £1. We meet from 11:00 to 12:30 monthly on a Tuesday and listen to members updates since the last meeting. This

gives individuals a chance to receive feedback from group members including Dorset Lady from Health Unlocked, whose support is highly valued. Afterwards we have pre-ordered lunch together from the cafe. We feel that the private space gives better opportunity to share our experiences and be heard, although we need funding to continue to use this space in the future. We aim to join with East Dorset for Consultant led meetings.

Catherine Spencer – Brighton
The Brighton Support group continues to thrive. We have 15 members and we have bi monthly meetings with the option of face to face or Zoom.

It is great that we can share things and mutually support each other.

Linda Evans – Havant
We currently have over 40 members who have joined us since the group was set up in May 2023. Not everyone attends all the meetings but we have a regular core number of 15 to 20. Several members have opted to maintain contact electronically so we keep them informed of visits and talks.

Colin Beevor, Senior Nurse Matron, maintains constant support from the local Rheumatology Dept for our group. He has arranged various practical sessions including information about Osteoporosis and Exercise with PMR & GCA. In addition to these, two of the department consultants have shared valuable up to date information about current research and treatments for both conditions. The question and answer sessions which followed these sessions were invaluable.

Lucille Baldwin – Great Yarmouth & Lowestoft
We have at present 11 members with 3 active GO's - myself being Admin.

We have been busy handing out posters to local surgeries, library and Age Connected to announce our presence in the community. I have created a Facebook page with our contact details and some information of the illnesses.

We have a member meeting on 11th June and another two scheduled for 10th September and 10th December. At the June meeting we have arranged for Consultant Rheumatologist Dr Makkuni to do a Q&A session for our members as it seems some have questions to ask. We are working on a Yoga teacher to come to the September meeting to talk about the importance of exercise and the GO's are meeting on 3rd June to discuss ideas for the December meeting and thereafter.

Catherine Orr – Sevenoaks, Tonbridge & Tunbridge Wells
The group meet every other month at our new venue in Southborough. The new venue is quieter and easier for conversation.

The meetings are usually on Wednesdays with occasional variation to accommodate anyone who cannot make this day.

Yvonne McGowan, Teresa Cook, Sue Barrass & Sue Hargreaves – Yorkshire
Yorkshire Support Group covers 4 locations, Ilkley, Leeds, Sheffield and York. This year we have held 16 meetings and 12 Zoom sessions. The attendance varied from 2 -10 also depending on location for the face-to-face meetings. These meetings are informal with a set agenda, held in a café or community room. The aim is to provide a structured approach for the group and put them at ease, enabling discussion and ample time for a question-and-answer session

In January we had Dr Claire Vandevelde as a specialist speaker in January for our Zoom Session. The topic was Osteoporosis and Bone Health. She gave an in depth talk with an excellent presentation followed by a Q&A session. We had more than 40 attend and it was very well received. Feedback was all positive.

In April for our next Zoom session, we chose to have a talk on Steroids and Diet given by Teresa Cook. Again, this attracted over 40 people as we extended our invitation to those on HealthUnlocked. We will be looking to follow this up to see who benefitted from the talk and found the information and support useful.

YSG has been working with Dr Sarah Mackie this year and her research team from Leeds Teaching Hospitals on the Paradox Project led by Lucas Coutin, Northern Project Lead. This came to an end in March and Lucas has now left the charity to work in Denmark. The Call-to-Action dissemination event held in Leeds was put on to showcase the outcomes of the program.

It was good for our members to have the opportunity to be involved in this research. Now the final report has been submitted for the Paradox Project we hope more funding will become available for further research project like this. Dr Mackie and her team are patient centred in their approach to research and treatment for PMR or GCA patients. It's not all about lab or test results it about the whole person as an individual. This attitude toward patients encourages participation in the focus groups.

Tina Manolis – Chichester
Since last year we have had 3 ladies join our group who have quite a number of health problems including the original ones so a marathon isn't an option for the Chichester group but at the end of the year we intend sending a donation from us all. At each and every group meeting they all say every time how much they have enjoyed our discussions and that it helps them so much which is nice to hear.

We are all very pleased that I found an upgrade room for our meetings which we tried out a couple of weeks ago with great success. So everyone is happy.

Derek White - Barnet

We have had several meetings with two meetings this year which were well attended for us (10 each) and we covered experiences of prednisolone, rheumys and pill splitting. New attendees were pleased to find the existence of the Charity and groups like ourselves.

Next meeting will be held in mid-October but yet to be confirmed.

Sue Stevens - High Wycombe

The High Wycombe group continue having meet ups on the second Wednesday of each month in the Riverside High Wycombe. We have three new members, two with GCA and one with PMR making a total of nine but not everyone comes every month.

Part B – Report from PMR-GCA Scotland

SCOTLAND REPORT FOR UK CHARITY'S ACCOUNTS 2025

We have enjoyed another busy year in Scotland which has seen our membership rise to 419 which is a significant increase from 331 at this point last year. We are not aware of any particular reason for such an increase, but the significant overhaul of our website in 2023 has increased our visibility on computer search engines which will have led more browsers to our website. The site continues to be a useful source of information for many people, both medical and non-medical, providing the initial point of contact for many new members.

We welcomed the addition of a new volunteer on the Helpline team during 2024 and since then another two new volunteers have come forward. This is a tremendous boost for such a vital service and we give our most sincere thanks to Helen and all of the team.

Five local support groups continue to meet regularly, monthly or bimonthly, in Aberdeen, Dundee, Glasgow, Edinburgh, and Inverness (Highland) and we estimate that about half of our members maintain contact with these groups. In addition, our online support group is now established and meets every three months replicating the ethos and content of our in-person groups.

At our AGM in 2024 we heard from Professor Neil Basu of the University of Glasgow who talked about his work on fatigue and different approaches to help patients cope with this common problem. He discussed various types of treatment including exercise, talking therapy, and education on control techniques. We also had a quick update from Dr Lisa Hutton on her involvement with setting up a Scottish site as part of the Sterling project which is investigating different drug treatments for relapsing PMR. These topics are extremely relevant to our everyday experiences as patients.

A main objective of our charity is to support and promote treatment and research activities into PMR and GCA. I am delighted to say that we have been able to resume our financial support of research work by making a grant payment of £2,000 to a project under the auspices of the University of Glasgow. The grant will go towards work looking at blood characteristics of GCA patients which may lead to new avenues of treatment other than steroids. This is exciting work but the bulk of our involvement in research is rather more mundane, but in some ways just as important. We are involved with a wide range of committees and working parties which contribute to research both domestically and internationally. Some of the committees and meetings support government planning and service delivery, whilst others are gathering patient data or views as part of research projects on diagnosis and treatments.

All the work mentioned above would not be possible without the efforts and support of all our members. I must, however, give special thanks to our Trustees, to our Helpline volunteers, and to the organisers of our support groups.