POLYMYALGIA RHEUMATICA AND GIANT CELL ARTERITIS UK

England & Wales · Charity number 1128723

Details

Other names	PMR-GCA UK
Status	Registered
Legal form	Charitable company
Company number	06763889
Registered	2009-03-20
Register	View on the Charity Commission register

Contact

Address	15 Stoneleigh Avenue Brighton BN1 8NP
Phone	03009995090
Email	info@pmrgca.org.uk
Website	www.pmrgca.org.uk

Activities

Objects: I 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 GROUPSII 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

Activities: PMRGCAuk is a national charity supporting those with the debilitating conditions Polymyalgia Rheumatica and Giant Cell Arteritis. We offer information and support, raise awareness amongst the public and clinicians and facilitate research into both conditions.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Education/training, Disability
- **Who:** People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups, The General Public/mankind

Geography

- **Area of benefit:** UNDEFINED. IN PRACTICE, NATIONAL AND SCOTLAND.
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£143,688	£137,068	-	-
2024-03-31	£116,645	£140,393	-	-
2023-03-31	£77,498	£103,683	-	-
2022-03-31	£86,044	£118,311	-	-
2021-03-31	£194,872	£78,620	-	-

Trustees

Name	Role	Appointed
Dr Vanessa Quick		2022-06-30
Fiona Katrine Johnson		2023-06-21
Gail Susan Booth		2023-12-06
Geoffrey Holroyd		2020-09-30
JANICE MADDOCK		2017-02-01
Madeline Whitlock		2026-04-01
Professor Margaret Fiona Bassendine		2025-09-06
Stephanie Anne Beer		2026-04-01
William Antony Mansfield		2023-12-06

Accounts

PMR GCA UK

Polymyalgia Rheumatica
& Giant Cell Arteritis UK

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.

Independent Examiner's Report

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: Gamage

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 £ 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	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

	Signature	Print Name	Date of approval dd/mm/yyyy
Signed by two trustees on behalf of all the trustees			
	Fiona Johnson	Fiona Johnson	06/09/2025
		Geoff Holroyd	06/09/2025

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	Year to
	31 Mar 25	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	Year to
	31 Mar 25	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.

Accounts

PMR GCA UK

Polymyalgia Rheumatica
& Giant Cell Arteritis UK

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 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.

CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

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: Gamage

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

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	**01/04/2023**	**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 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	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	Year to
	31 Mar 24	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	Year to
	31 Mar 24	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 01 Apr 23**	**Income**	**Expenditure**	**Balance at 31 Mar 24**
	£	**£**	**£**	**£**
Stone King Legacy	18,686	-	-	18,686
James Tudor	100	-	- 100	-
Anonymous Grantor	1,575	-	- 875	700
Wellcome Trust	5,981	-	-	5,981
Kent Community Foundation	5,437	-	- 5,437	-
Sussex Community Foundation	2,680	-	- 2,680	-
Sevenoaks Distric Council	1,400	-	- 1,400	-
Member Donation	11,502	-	- 9,702	1,800
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	57,361	-	- 20,194	37,167

Restricted Income **2022/23**	**Balance at 01 Apr 22**	**Income**	**Expenditure**	**Balance at 31 Mar 23**
	£	**£**	**£**	**£**
Stone King Legacy	21,186	-	- 2,500	18,686
James Tudor	-	1,500	- 1,400	100
Anonymous Grantor	-	1,575	-	1,575
Garfield Weston	1,029	-	- 1,029	-
Wellcome Trust	5,981	-	-	5,981
Kent Community Foundation	5,025	4,857	- 4,445	5,437
SussexCommunity Foundation	4,726	-	- 2,046	2,680
Tesco	510	-	- 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	- 11,930	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 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.

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 Sedbergh. 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.

Accounts

PMR GCA UK

Polymyalgia Rheumatica
& Giant Cell Arteritis UK

Accounts
and
Annual Report
2022 - 2023

Message from Chair of trustees

As the scale and urgency of the Covid-19 pandemic has subsided, I'm sure we all feel huge gratitude to the scientists, health professionals, organisers and volunteers who created and rolled out the immunisations that protected so many, particularly the vulnerable. And we can take stock of the pandemic's – on each of us, on families, and on the nation. In addition, Covid-19 has significantly altered the way organisations work, and we at PMRGCAuk have not been exempt from that. Paradoxically I feel we have emerged stronger from the health crisis, with new ways of working and a wider reach to our members, and also to others with or affected by PMR and GCA who are not members (though we hope they will become so!).

Central to that change of course has been the adoption of remote access and Zoom technology, most obviously affecting our Annual General Meeting. Although the face-to-face personal networking has been lost – and some members as well as our staff and trustees have missed that – many more people have participated, and so 2023 will also be by Zoom. Similarly, some of our larger support groups have stayed with remote meetings. However, at the same time we can all welcome the return of the chance to choose how and when our support groups can meet. For the future, PMRGCAuk will continue to help support groups to do whichever format they choose. Importantly, we will also continue to exploit Zoom to broadcast the regular webinars which are so popular.

Which leads me on to thank our experts who have 'zoomed' for us – Sarah Mackie (one of our patrons) and Jo Robson, Sarah Leyland from the Royal Osteoporosis Society, Sara Muller and Chetan Mukhtyar, during the year's AGM/Members' Day and PMRGCAuk week, and to all who helped fundraise during that week and at other times.

The annual report gives much more detail of each of our activities – particularly the telephone helpline, the support groups, and the HealthUnlocked forum. Each of these is totally dependent on our volunteers, who do this for no other reward than that of helping others. We are enormously grateful to them. But – importantly – we need to recruit more people to help, particularly for the helpline and as advisers on HealthUnlocked: please contact us if you would like to help – email info@pmrgca.org.uk. The report also outlines the research grant that we were enabled to give following a generous donation from one of our members, which will provide important information on how PMR is being managed 'in the real world'. This is an important step to becoming involved in research, and in the near future we have other research projects planned. As the charity representing the interests of people with PMR and GCA, we have an important role both in helping researchers, but also in helping drive the research agenda. I should also mention our website, and Newswire, which following their recent design and content upgrades have become even more informative and impressive.

We are also of course totally dependent on our staff – particularly Fran Benson, whose many responsibilities include the production of Newswire, and above all Candy Horsbrugh our director who keeps everything together; and I also want to thank my fellow trustees who make such a major contribution.

Humphrey Hodgson
Chair of Trustees

PMRGCAuk is an absolute lifeline with information about a condition that very few people understand.

Membership

Membership - our driving force

Our members are vital to the work we do, from shaping our services and strategy to acting as ambassadors and fundraisers for the charity.

Our membership fee is still only £15 a year and by the end of March 2023 we had 1585 members. This includes patient, friend and professional members of which 370 were new members during 2022/2023.

While members come and go as people go into remission, 25% of our membership have been with us for five years or more.

"The support that I have received as a member of PMRGCAuk has been invaluable – the magazine, webinars, website, staff, volunteers. I found it difficult to understand what had happened to me, how my life had changed so suddenly, and you made me feel less alone and more able to sort myself out. Thank you."

"Really appreciate the charity doing the webinars and making them available to the members."

"It's great feeling involved, that I'm part of a wider community of people suffering from the same disease."

Members' Day

Our Members' Day and AGM 2022 took place online. Our expert speakers from the medical and research community, who all took the time to answer some of our members' questions, were Dr Sarah Mackie and Dr Jo Robson

Dr Sarah Mackie, Associate Professor and Consultant Rheumatologist at the University of Leeds spoke about the PMR Voices project that she led during the winter of 2021 which was a patient involvement project in PMR and included two patients (Lorna Neill, Margaret Grover) and two Leeds-based patient and public involvement specialists (Amy Rebane, Hanif Ismail), as well as Zoom discussions with many of our own members and clinicians.

Dr Jo Robson, Associate Professor in Rheumatology, UWE Bristol and Bristol Royal Infirmary's talk was on the development of a patient reported outcome measure (PROM) questionnaire to measure the impact on quality of life from having giant cell arteritis. Patient and clinician feedback was pretty positive about making joint decisions and improved communication. Clinicians acknowledged that it enabled patients to discuss their anxieties and concerns. Patients said that they felt it helped to manage the GCA.

Feedback from attendees:

- *The whole thing was excellent.*
- *Personally, the fact that my husband watched from beginning to end and that he was extremely impressed with the high level of support available for PMR/GCA patients. The quality of content enabled greater understanding for him. Everything was described in terms easily understood by those of us who have little/no scientific background.*
- *Another chance to learn a little more.*
- *Just a very big thank you for providing such informative and enjoyable sessions they are really helping me understand my conditions (GCA & PMR & Osteoarthritis). Comprehension of the conditions and the ongoing research gives me hope that I can recover from GCA and hopefully PMA and reduce/ stop Prednisolone and Methotrexate at some point.*
- *Just -Thank you so much for all the support you give The Webinar lectures and the magazine and of course the Forum*
- *Gratitude, that is my comment. Gratitude for the charity, forum, the wise-old hands fielding people's concerns so well....without giving medical advice. Especially in the states, we have so very much to learn about GCA...the more I know, the better patient I can be.*

PMRGCAuk Week 6 – 12 June 2022

PMRGCAUK WEEK

PMRGCAuk week 2022 celebrations remained online and took place in June. We were delighted to welcome our three guest speakers and more than 200 members and guests to our PMRGCAuk Week webinars.

Sarah Leyland from the Royal Osteoporosis Society (ROS) spoke about **osteoporosis, steroids and PMR**. She gave a detailed explanation of what osteoporosis is, its symptoms and causes, the impact of steroids and what patients can do to help themselves.

The second webinar, with our trustee Sara Muller. Sara spoke about the **long-term use of glucocorticoids for PMR**, which was a follow-up of a PMR Cohort Study undertaken at Keele University

The third webinar was with Dr Chetan Mukhtyar whose talk was **GCA: A Giant Update**. He spoke in depth about GCA, explaining what it actually is and the range of symptoms someone might experience as well as the treatment and care they should expect.

We also launched our 2023 calendar photo competition after the success of our previous year's calendars photo competition. This year we had over twenty-two entrants and 75 photos to choose from. Thank you to everyone who sent in a photo.

Thank you to all our members who gave donations for PMRGCAuk Week and for the lovely messages of thanks. We raised over £250 in donations from PMRGCAuk Week and £1,400 from the sale of calendars and Christmas cards. Thank you to Pat Fedi, our volunteer who sent out the Christmas cards and to Sue Beesty who sent out the calendars.

Feedback from attendees:

"Thank you for a very clear presentation, very helpful."

"PMRGCA UK website provides comprehensive information and help I will now also use ROS website too."

"Thanks, Sarah. This has been an excellent session. Very professional manner and content while answering the questions of a reasonably well-informed audience!"

"thanks to all, appreciated - great work by both organisations."

"excellent presentation - very informative. Thank you"

"Thank you very much. Very helpful to me as a relative newbie to PMR and GCA"

"Thanks very interesting & informative"

"Thank you it answered all my questions and more. Very useful."

" Brilliant, so much information which I can relate to GCA and PMR and very useful information from other participants thank you so much."

Providing support and information

We provide support through our Telephone Helpline, our national network of Support Groups and through our online HealthUnlocked forum.

Telephone Helpline

The Helpline volunteers spoke to 368 (403) callers from April 2022 - March 2023 with less calls during the summer months and in December. The main reasons for calling are for information about PMR and/or GCA; questions and concerns about taking and reducing steroids; needing support generally with managing their condition and to talk to someone who understands through having had PMR or GCA. Calls may last from 5 - 45 minutes each, with an average of 15- 20 minutes, depending on the need of the caller.

The helpline team consisted of six volunteers during this time taking calls from Monday to Friday 9am to 5pm. If the call is unable to be answered immediately the caller is invited to leave a message and will be called back.

Statistics

- 75% of callers had PMR; 15% GCA; 10% had both.
- The average age of callers was 71 and 77% of callers were women.
- 47% were newly or recently diagnosed; 44% had been diagnosed between 1-4 years and 7% over 5 years.
- 71% of the people we speak to are first time callers and 29% of all callers have called more than once, with a small core of these who have called several times.
- 84% of calls were for information and at the end of their call many callers were directed to the website for more information or sent an information pack.
- 85% of callers are asking for information about the conditions, medication and management of steroid reduction.
- Almost half of all callers appear to need to talk about their concerns and required a supportive understanding ear from someone who knows what it is like to have the condition(s) and to be on long term steroids.
- 5% of callers asked questions about steroid sparing medication.
- 15% of callers were unhappy and expressed dissatisfaction with their management locally and felt especially unsupported with the difficulty accessing their medical team or other support.
- 20% of callers are recorded as being members of PMRGCAuk.

Many callers express their gratitude directly of being able to speak with someone who understands what they are experiencing and know how they feel. We aim to answer most of the calls in person, but this is not always possible and not all callers feel able to leave a message which we regret as we will always call back if invited to.

The funding for the Helpline training with Alice Hanscomb has continued, thanks to the James Tudor Foundation, for the third year running. This is invaluable for our support and improving the support we give to others.

"I am very grateful to the Helpline as it was helpful to talk to someone who understood and could help me get my mind straight." ***Helpline caller***
"I have found the polymyalgia helpline invaluable." ***Cumbria group member***

Support groups

Having a dedicated resource focusing on support groups, throughout the country, has had a positive impact on the number of active support groups and therefore increased the number of members we can support.

Since the pandemic, the biggest change has been the joy of people once again being able to meet in person. Simple cafe meetups seem to be the preferred way forward, where the benefit of meeting someone who understands PMR and/or GCA is immense and cannot be underestimated. We have been busy restarting groups, setting up brand new groups and helping with the smooth transition as new GOs take over from departing ones. Groups are running from Kendal to Truro and some of the brand-new groups this year include Ashford Kent, Luton & St Albans, Chichester, Haywards Heath and Havant (Portsmouth). We have also been able to restart some existing groups such as Harlow, London, Sevenoaks, Tonbridge and Tunbridge Wells, Cambridge, Maidstone and Eastbourne helped by the support of Regional Organisers and very dedicated and enthusiastic local Group Organisers. This is despite the number of challenges facing groups which include finding suitable meeting venues, retaining and/or recruiting GOs and raising awareness. We have successfully increased attendance at meetings by ensuring our website is always up to date, improving posters and leaflets and increasing our use of social media. Zoom meetings still hold a vital role and enable those unable to get to a local in person meeting to continue to access support and companionship.

Our GOs are all incredible volunteers and it's thanks to them we can support a far greater number of members. As a charity, we always face the challenge of increasing awareness but with the growth of local groups and members, we can spread the word and continue to grow our presence.

Don't lose heart! I was on my 3rd attempt that I finally arrived at 0 Pred without needing to go back. I did feel very nervous without the anchor of Pred, but this worked for me. It's been almost 2 years without Pred, and yes, I do feel really well. So, hope this helps!
Kendal group member

I'm very pleased to be part of a growing support group for PMR, I look forward to our monthly meetings and feel I have made some new friends.
Kendal group member

Rosemary, Kendal Support Group
I had PMR for 1 year and the first Covid lockdown March 2020. There was no functioning support group in Cumbria or Northwest so I looked further afield, found the Yorkshire Support Group and asked if I could join them .I was welcomed and their Zoom meetings were a lifeline for me.

When restrictions eased, I contacted Candy about offering a coffee and chat meeting for any interested members in my area. She wrote to several, set up the contact email and we got a few responses. I fixed on my nearest town, Kendal in an easily accessible spacious cafe with car park .My first meeting was with C and we had a really enjoyable conversation exchanging experiences and information etc.

I then started organising meetings about 6- 8 weeks at the same venue from 11am to 1pm aiming to be friendly, informal and mutual supportive. Our numbers grew up to 6 people at each and that *seems to work well. Some people came to know about the group via the PMR/GCA helpline or website.*

We draw from Lancashire, North Yorkshire and far northwest Cumbria - the geography, transport and weather are challenges to everyone wanting to attending our cafe gatherings.

In order to reach out to more people I have recently been distributing posters and leaflets (designed and printed by the charity) to GP surgeries, chemists, libraries ,churches, Age UK, charities, cafes, community centres and public notice boards in many villages and towns in the wider rural area. This has produced 3 extra members so far to add to the mailing list. Group members have also taken posters to display in their locality.

The charity also sent an email to members in the relevant postcodes notifying them of the group and this produced 3 more new people.

We currently have 12 people on the email list covering a wide area, some of whom I have yet to meet. The group consist of people with PMR and tapering steroids, people with GCA, 2people in remission from PMR , 2 with a change of diagnosis and several with accompanying complex conditions. We have working parents but are predominately over 60 retired and female. Some people see rheumatologists and others access GP/nurse services and all with mixed experiences.

It has been a very interesting experience and I hope the beginning of offering more direct support to people affected by PMR/GCA in this region. My aspiration would be to stimulate interest in starting more cafe and chat support groups in the northwest of England through diverse means.

PMRGCAuk INFORMATION PACKS

We have Information packs for newly diagnosed people (or for people who have just found the charity) with PMR and GCA. They consist of information about the charity, British Society for Rheumatology (BSR) guidelines on PMR/GCA, our Symptoms leaflet and our How We Can Help leaflet and booklets on PMR and GCA. These can be requested via our website for a digital or hard copy version. In the last few years, the numbers of Information Packs which have been sent out has increased (details below). This could be due to more people being diagnosed with either condition or but more likely due to the charity's increased presence due to work we have done with researchers, our improved website and the support we give to people via our support groups, helpline and our online forum, HealthUnlocked. The majority of our hard copy information packs are requested via our website, but a number also come directly via our Helpline who request them on behalf of people who have called the Helpline for support.

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

We would like to thank Laurene Brooks, our volunteer who sends out all hard copy information packs and keeps details and up to date information on packs sent out.

HealthUnlocked forum

Our PMRGCAuk HealthUnlocked forum is an online patient-led community, enabling members to share their experiences and offer support. Members continue to support each other and engage with the forum on a regular forum; it is a great space not just for those newly diagnosed, but anyone who wants to share experiences and feel less alone. It is a vital and vibrant place and numbers of members continue to grow. HealthUnlocked is administrated and moderated by PMRGCAuk staff and trustees. We are very grateful for all the support we receive on HealthUnlocked, but particularly to our volunteers known as PMRPro, DorsetLady and Mrs Nails (who stepped down during the year), whose constant work and support is invaluable to the smooth running of the forum.

At the end of March 2023, we had 4,665 active members, with on average about 190 new members signing up each month.

Quotes about the HealthUnlocked forum

Just a thank you for all the help and support I received with my flare question, too many to answer individually. As always, I don't know how I would have managed without this site. Very grateful and it helps to know so many are others are grappling with this illness, let's hope for all of us to have better days. **HealthUnlocked member, 2023**

Just to thank this group for the unending support it gives us sufferers. It is so much appreciated.
HealthUnlocked member, 2023

I haven't written very much on the forum but I do read the comments every day and have found them very helpful and supportive. The volunteers do a great job. Sincere thanks to you.
HealthUnlocked member, 2023

Raising awareness and funds

James Tudor Foundation - £1,500 towards the continued training of our Helpline volunteers

Anonymous donation from a foundation who donated £1575 towards training of our Helpline volunteers for 23/24

Regional Lions Clubs donated to some of our Support Groups:
£200 from the Pinner Lions Club to our Pinner Support Group
£250 from the Dartford Lions Club to our Dartford Support Group
£250 from the Whitstable Lions Club to our Whitstable Support Group

Christmas Card and calendar 2022 sales – we raised £1,400 from sales of Christmas cards. Thank you to Pat Fedi, our volunteer who sent out all the Christmas cards and to Sue Barrass, who sent out the calendars.

Supporting research

- £50,000 grant towards research into PMR

In March 2021, PMRGCAuk received a very generous donation form one of our members of £50,000 for a grant towards research into PMR.

In 2022/23 we awarded £10,000 of this donation to Anne O'Brien of Keele University and her team to create, with patients' and health professionals' input, a PMR-specific exercise education leaflet looking at safe exercise, the importance of keeping moving and pacing oneself, maintaining physical function and independence. Exercise is advocated in international PMR guidelines and many patients want to engage in exercise but are unsure of what they should be doing, and many need reassurance that exercise is not harmful. This study, and the resulting leaflet, will help to address patients' concerns in this area.

(We awarded a substantial sum of this to Dr Max Yates in January 2022 to research "Improving the quality of glucocorticoid prescribing for PMR in England". This will be completed by December 2023.)

We are immensely grateful to the grant maker for their very generous grant.

PMRGCA

Annual Report and Accounts for 2022/23

Financial Review

This year we recorded a deficit on all activities of £26,185 as a result of increasing staffing levels to further develop the services provided to our users. The capacity to do so comes from legacies in previous years which increased our reserves.

Income

Income for the year was £77,498 of which £59,957 was from the subscriptions and donations of the charity's users with a further £10,332 of grant income. There were smaller levels of income from other fundraising activities and from investment income.

Expenditure

Expenditure for the year was £103,683 of which the major cost was salaries totalling £75,291. Expenditure on restricted funds includes the continuing development of the support group networks in Kent and Sussex for which we have received specific grant funding from the Kent and Sussex Community Foundations and the helpline volunteer training programme. The ongoing development of the support group networks in other areas is currently funded from general reserves.

Balance Sheet

As a result of the deficit incurred in the year total funds reduced by £26,185 to £239,373. 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 £16,100, Restricted Reserves reduced by £2,598 and the General Reserve reduced by £7,487 to £69,314 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.

CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

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 2023 **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: Gamage **Date:** 20/08/2023

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

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	**01/04/2022**	**To**	Period end date	**31/03/2023**

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	59,957	-	-	59,957	66,421
Charitable activities	S02	2,417	9,332	-	11,749	16,953
Other trading activities	S03	1,983	-	-	1,983	2,294
Investments	S04	3,809	-		3,809	376
Separate material item of income	S05	-	-	-	-	-
Other	S06		-	-	-	-
Total	S07	68,166	9,332	-	77,498	86,044
Resources expended (Note 4)						
Expenditure on:						
Raising funds	S08	15,675	-	-	15,675	13,439
Charitable activities	S09	72,383	11,930	-	84,313	63,915
Separate material item of expense	S10	-	0	-	0	38,498
Other	S11	3,695	-	-	3,695	2,459
Total	S12	91,753	11,930	-	103,683	118,311
Net income/(expenditure) before tax for the reporting period	S13	- 23,587	- 2,598	-	- 26,185	- 32,267
Tax payable	S14	-	-	-	-	-
Net income/(expenditure) after tax before investment gains/(losses)	S15	- 23,587	- 2,598	-	- 26,185	- 32,267
Net gains/(losses) on investments	S16	-	-	-	-	-
Net income/(expenditure)	S17	- 23,587	- 2,598	-	- 26,185	- 32,267
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	- 23,587	- 2,598	-	- 26,185	- 32,267
Reconciliation of funds:						
Total funds brought forward	S23	205,599	59,959	-	265,558	297,825
Total funds carried forward	S24	182,012	57,361	-	239,373	265,558

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	8,283	-	-	8,283	8,101
Investments	B08	137,834	43,438	-	181,272	179,973
Cash at bank and in hand	B09	38,817	13,923	-	52,740	78,788
Total current assets	B10	184,934	57,361	-	242,295	266,862
Creditors: amounts falling due within one year (Note 8)	B11	2,922	-	-	2,922	1,304
Net current assets/(liabilities)	B12	182,012	57,361	-	239,373	265,558
Total assets less current liabilities	B13	182,012	57,361	-	239,373	265,558
Creditors: amounts falling due after one year	B14	-	-	-	-	-
Provisions for liabilities	B15	-	-	-	-	-
Total net assets or liabilities	B16	182,012	57,361	-	239,373	265,558
Funds of the Charity						
Endowment funds	B17	-			-	-
Restricted income funds (Note 9)	B18		57,361		57,361	59,959
Unrestricted funds (Note 11)	B19	182,012		-	182,012	205,599
Revaluation reserve	B20				-	
Total funds	B21	182,012	57,361	-	239,373	265,558

Signed by two trustees on behalf of all the trustees

Signature	Print Name	Date of approval dd/mm/yyyy
	Humphrey Hodgson	25/09/2023
G. Holroyd	Geoff Holroyd	25/09/2023

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 23	Year to 31 Mar 22
	£	£
Membership fees	21,280	20,685
Donations	32,730	34,780
Gift Aid	5,947	7,648
	59,957	63,113
Legacies	-	3,308
	59,957	66,421

Membership fees and general donations have remained stable year on year.

4. Charitable Expenditure

	Year to 31 Mar 23	Year to 31 Mar 22
	£	£
Staff costs	62,130	48,731
Funding of research project	-	38,498
Other costs	22,183	15,185
	84,313	102,414

5. Trustees

None of the trustees received any remuneration during the year. There were no trustee expenses during the year (£138.63 in 2021/22).

6. Employees

Employees		
	Year to	**Year to**
	31 Mar 23	**31 Mar 22**
Employment costs	**£**	**£**
Wages and salaries	73,782	58,502
Taxes	-	335
Pensions	1,509	1,256
	75,291	60,093
The average number of employees		
during the year was	4.7	3.3

The average number of employees on a full time equivalent basis was 2.5 (2021/22: 2.0).

7. Debtors

	Year to	**Year to**
	31 Mar 23	**31 Mar 22**
	£	**£**
Gift Aid accrual	6,000	7,750
Investment Interest	2,283	351
	8,283	8,101

8. Creditors: Amounts falling due within one year

	Year to	**Year to**
	31 Mar 23	**31 Mar 22**
	£	**£**
Independent Examiner's fee	700	600
Social security and pensions costs	266	237
Other creditors	1,956	467
	2,922	1,304

9. Restricted Funds

2022/23	**Balance at**	**Income**	**Expenditure**	**Balance at**
	01 Apr 22			**31 Mar 23**
	£	**£**	**£**	**£**
Stone King Legacy	21,186	-	- 2,500	18,686
James Tudor	-	1,500	- 1,400	100
Anonymous Grantor	-	1,575	-	1,575
Garfield Weston	1,029	-	- 1,029	-
Wellcome Trust	5,981	-	-	5,981
Kent Community Foundation	5,025	4,857	- 4,445	5,437
Sussex Community Foundation	4,726	-	- 2,046	2,680
Tesco	510	-	- 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	- 11,930	57,361

Restricted Income				
2021/22	**Balance at**	**Income**	**Expenditure**	**Balance at**
	01 Apr 21			**31 Mar 22**
	£	**£**	**£**	**£**
Stone King Legacy	24,886	-	- 3,700	21,186
James Tudor	-	1,500	- 1,500	-
Garfield Weston	2,472	-	- 1,443	1,029
Wellcome Trust	5,981	-	-	5,981
Masonic Trust	100	3,000	- 3,100	-
Kent Community Foundation	4,000	4,980	- 3,955	5,025
SussexCommunity Foundation	-	4,864	- 138	4,726
Tesco	-	1,000	- 490	510
Member Donation	50,000	-	- 38,498	11,502
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	97,439	15,344	- 52,824	59,959

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
Masonic Trust	Befriending project
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

Prior year adjustment to Restricted Funds

Over the past three accounting periods certain items of expenditure on the production and distribution of information packs for members have been misclassified as general expenses when they should have been recorded against restricted income.

The impact is not material, the balance of the Restricted Income reserve at 31 March 2023 is £3,800 lower than it would have been without these adjustments. General reserves are higher by the same amount.

10. Legacies Reserve

Legacies Reserve		
	Year to	**Year to**
	31 Mar 23	**31 Mar 22**
	£	**£**
Opening Balance	128,799	143,419
Received in year	-	3,308
Transferred to General Reserve	- 16,100	- 17,928
Closing Balance	112,699	128,799

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 23	**31 Mar 22**
	£	**£**
Restricted Income	57,361	59,959
Legacies Reserve	112,699	128,799
General Reserve	69,313	76,800
Total Reserves	239,373	265,558

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 do not have an office. We work virtually. Our address is a mailbox. All but one of our staff are part time. You can rest assured that we spend every penny 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, Dr Vanessa Quick, Sara Muller, Christine Young, and Wendy Morrison.

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), Fran Benson (Membership Secretary & Assistant Director), Neelam Russell (Kent Regional Organiser, Phone Friends Coordinator to November 2022 and National Support Group Manager from November 2022), Phil Cotterell (Sussex Regional Organiser from September 2022) and Charon Balarabe (Administrative Assistant) and Maria Millan (Administrative Assistant maternity cover, May 2022 to March 2023).

About the charity

PMRGCAuk is the national patients' information and support charity for those with the chronic and debilitating auto-immune conditions polymyalgia rheumatica and giant cell arteritis. The two related conditions, the cause of which are currently unknown, drastically impact the quality of life of those affected - from the inability to perform everyday tasks as a result of severely restricted mobility to chronic pain, fatigue and depression. In the case of the more serious condition GCA, catastrophic blindness can occur if it is not diagnosed and treated swiftly and sadly there have been cases of some who, having lost their sight, felt so hopeless that they committed suicide. Typically affecting those over 72, around 1 in 1,000 develop PMR each year. With both conditions little known and poorly understood, PMRGCAuk is the only charity in existence dedicated to promoting knowledge and awareness amongst the public, with those diagnosed and their families, as well as raising the profile of the conditions with the medical profession.

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.

Bedfordshire Support Group
We have had several "coffee meetings" of between 2 and 10 members during the past year. We still have 16 members and our WhatsApp group is always available.

Some people, who have managed to get off prednisolone , still like to keep in contact and, of course, they can come to meetings whenever they want, to give hope to others.

Brighton Support Group
The Brighton Group continues to meet every two months with an option of face to face in a member's home or via Zoom. We have a core of about ten members but there are 14 on my contact list. We are friendly and supportive and with our varied experiences are able to offer valued support to those recently diagnosed or misdiagnosed!

Cambridge Support Group
The Cambridge group is slowly getting going again post Covid. We meet in central Cambridge at the moment in John Lewis' cafe but this is still under consideration. At present we meet every couple of months and seek to support each other with coffee and chat recognising that it is much easier these days to access a lot of information on the internet. We are a small friendly group and all are welcome.

Harlow Support Group
Covid almost saw the end of our Group. But in 2023 we have picked up numbers and are now twelve strong. We've recently moved to a local, convivial, pub in Theydon Bois. A large free car park and free meeting area, make it ideal.

Our meetings are informal, no set agenda, but have general lively discussions where we learn more about PMR/GCA and exchange tips. At one meeting we discussed diet and exercise and the benefits of both to our situation and will build upon that.

Kendall (Cumbria) Support Group
We have meetings about 6- 8 weeks at the same venue from 11am to 1pm aiming to be friendly, informal and mutual supportive. We draw from Lancashire, North Yorkshire and far northwest Cumbria - the geography, transport and weather are challenges to everyone wanting to attending our cafe gatherings.

We distribute Kendal/PMRGCAuk leaflets to GP surgeries, chemists, libraries ,churches, Age UK, charities, cafes, community centres and public notice boards in many villages and towns in the wider rural area. This has produced 3 extra members so far!

We currently have 12 people on the email list covering a wide area. The group consists of people with PMR and tapering steroids, people with GCA, 2 people in remission from PMR, 2 with a change of diagnosis and several with accompanying complex conditions. We have working parents but are predominately over 60 retired and female. Some people see rheumatologists and others access GP/nurse services and all with mixed experiences.

It has been a very interesting experience and I hope the beginning of offering more direct support to people affected by PMR/GCA in this region. My aspiration would be to stimulate interest in starting more cafe and chat support groups in the northwest of England through diverse means.

Maidstone Support Group

With encouragement from Neelam Russell, we have been able to revive our support group in Maidstone, meeting up monthly in person since November. We have welcomed some new members along with a few who used to come along before the lull of Covid-19, and have enjoyed sharing experiences and passing on tips, together. Attendance varies each month, as does the chat, and In March 2023 we heard about the work of the Maidstone Lions locally, including their project to provide a defibrillator for every local school.

Orpington Support Group

The Orpington Support Group exists to help anyone affected by PMR & GCA in the London Borough of Bromley. We usually have between 10 and 20 attendees. Yet there are 58,275 (2021 census) over 65-year-olds living in Bromley (35,887 women) and it is frustratingly difficult to let those affected by PMR and/or GCA know that we are here for them. We still try to find ways to spread the word in the usual way with posters, local magazines, local groups, etc.

However, with the support of our local consultant rheumatologist and rheumatology nurse, who have introduced us to some very good speakers this year, plus Bromley Lions Club that has provided us with funds, our big aim for the next charity year is to use the donated money for a lunchtime training session or sessions for local GPs who do not always recognise the symptoms of these two conditions and who rarely point their patients in our direction. Our plan is to approach the Bromley GP Alliance, South East London ICS to find out who knows about GP education programmes and the GP Training Program for junior doctors - BETH (bromleytraininghub.co.uk).

Pinner and Ruislip Support Group

The Pinner and Ruislip Groups continue to run alternating monthly since the new Pinner Group was established in February 2020. The numbers in Pinner have remained constant and saw the reintroduction of refreshments. The Ruislip group has seen numbers increase and a core group has emerged. Various topics have been discussed including exercise and nutrition as well as the continuing issues around tapering. A speaker from the Lions attended to talk about their 'Message in a Bottle' scheme - finding appropriate speakers has not been easy, the hope is for more this year. One member of the Ruislip Group signposted the Group Organiser to their local U3A and she went to talk to 105 of their members in order to raise awareness of PMR and GCA.

Sevenoaks, Tonbridge and Tunbridge Wells Support Group

The recently formed Sevenoaks, Tonbridge and Tunbridge Well support group has gone from strength to strength this year with a mixture of old and new faces enjoying the support and companionship of in-person meetings once again.

This year the group has had several varied meetings including watching a webinar provided by the charity, a fundraising event at a local garden centre, a seated exercise class, a talk by Kent Air Ambulance as well as a very successful summer and Christmas lunch. The group has also enjoyed regular coffee and chat meetings and now has a new group organiser ensuring it continues to flourish in 2023.

Trent Valley Support Group

The Trent Valley support group has been meeting every 2 months over the past year, with an increased number of people attending, including an increase in the number of men attending the group. The meetings usually consist of an input from each member, as to their current status with PMR/GCA. However, at the December meeting we had a talk from a fire fighter on "Safety in the Home" (our meetings are currently held at the local fire station community room).

Truro Support Group

The Truro Support group has continued to run monthly meetings in person all year at the Truro Golf Club. They are the only group in Cornwall and people do come from far and wide. In February this year Margaret & John Nash, founders of the group, retired & Anne Pollard took over as co-ordinator, with support from Lorna Cann as treasurer. Meetings are very well attended, usually around 12-15, and we have welcomed 2-3 new members at most meetings. We generally just have a chat where people are relaxed enough to share their experience. We are lucky that Dr Mark Hughes, consultant rheumatologist, pops in occasionally and his advice is much appreciated.

WedPM Zoom Support Group

The WedPM Zoom Support Group continues to meet with between 10 and 15 members. Currently members are from the London boroughs, Kent, East & West Sussex, Nottinghamshire, Leicestershire, Norfolk, the USA and more! Where time zones allow, everyone is welcome.

Meetings are very similar to face-to-face meetings and everyone shares the ups and downs of flares, steroid tapering and much more from the comfort of their own home. Between the members and the PMRGCAuk website we have access to a wealth of information on all things PMR and GCA which is especially helpful to the newly diagnosed or those who have only just found us after years of struggling alone.

This year we had a speaker from the St John's Ambulance Brigade. He spoke on emergency first aid. One benefit of our Zoom meetings is being able to share screens so I can show members the charity website, recorded webinars or even YouTube videos.

Welwyn Garden City Support Group

We are still holding meetings mostly on the first Friday of the month on Zoom. Most members who Zoom are unable to travel so the group might need to hold two meetings which will cover everyone.

Whitstable Support Group
The group in Whitstable has been very lucky to keep meeting face to face when permitted. We started 2 years ago as a group of 3 people & now have up to 17 each month, really encouraging and worthwhile.

We kicked off April 22 with a visit from Whitstable Lions giving us a well-received talk about their Green Bottles & subsequently they kindly donated £250 to the group. We've had Seated Exercises, social meetings & a summer lunch. After the summer break there we watched some of the charity webinars and was an excellent Xmas Lunch & a new member who arrived on the off chance!

The New Year saw us having a general catch up & at our February session there was a unanimous vote to have a private room for every meeting as it was felt people were more likely to speak of personal issues and also so many of us are hard of hearing these days, be it PMR or old age! We are proud that by increasing our fee to £4 we are now a self-supporting group. Some members prefer just to relax & have a catch up chat while others love the webinars & speaker slots so it's good to mix it up & hopefully keep everyone happy. We are so lucky to have the most amazing meeting facilities which cater for everything we need, these days it's more like a friendship group - long may it last!

Worthing Support Group
During the past year our membership has increased from 15 to 21 and we've settled down to two-monthly meetings in a room at the local Community Centre where we've had talks from our local Lions and another from an Admiral Nurse, and an exercise session with a qualified fitness instructor. We also have two-monthly coffee meetups in between our meetings and we also keep in touch via our WhatsApp group.

Our photograph appeared in the local newspapers, thanks to Phil Cotterell the Sussex Regional Organiser, and we recently donated £100 to the charity for PMRGCAuk Week.

Yorkshire Support Group
We held our first face to face meeting after Covid on 2nd November in the Ilkley Café Co, Ilkley. Until November we were having monthly Zoom meeting to ensure our members had access to the support they needed whilst being unable to get out and about. Some of the members were still wary of meeting in public places or using public transport. Since then, we have had 3 more meetings. We have 6 people attend and it was different members each time very much the same as the Zoom sessions. We have not used the Leeds venue this year due to city centre changes in and around John Lewis where we use their Community Hub. One member of our group has branched out and set up a meeting in Kendal to reach those in Cumbria, she now has 12 members. We need to encourage more members of our group to try this if there is nothing close enough in their area. Just coffee and a chat can help so many to get support from likeminded people in a safe confidential environment. Yorkshire is the only group in the North but with Zoom we can reach a wider audience and anyone is welcome regardless of where they live.

Part B – Report from PMR-GCA Scotland

This past year saw us making further progress towards recovery from Covid lockdowns and the resulting isolation. We remained available for contact by members and non-members through the website and the ever-important Helpline team. Whilst we continued to host some Zoom meetings, I am delighted to say that in-person meetings resumed for some local support groups. Personal contact, whether in person or remotely, is for me the best support that the charity can deliver whether it involves lending an ear for medical issues or support on more personal matters. We held four Zoom meetings in the year which were enjoyed by many members and which usually took the form of a topical presentation followed by general questions and discussion. Our AGM was again held online and whilst that helps to keep costs down, there is a significant trade-off in the loss of personal contact.

During the year the website was rebuilt and launched in mid-January 2023. As well as the new look, the website provides an improved layout giving easier access for users and a better overall experience. We have also improved search engine optimisation which, in layman's terms, means that the site will be easier to find on 'Google' making it more accessible for newcomers.

The other main objective of the charity is to promote research activities into PMR and GCA. Throughout the year the charity has been represented in a variety of committees and research activities, particularly with the involvement of Lorna Neill and David Carrott. We are keen to revive our practice of offering financial support to projects that meet our objectives and we have started some research ourselves to see if we can encourage the development of more standardised nationwide procedures to assist with faster diagnosis of GCA in an attempt to reduce incidences which can lead to loss of sight. Such an expansion of our activity will require a targeted campaign to generate financial resources.

We have completed the processes to convert the charity into a SCIO (a Scottish Charitable Incorporated Organisation). There is a new constitution in place for the SCIO, but our objectives and principles remain the same.

Harvie Findlay was our Treasurer for many years and intimated a desire to stand down back in 2021. He continued to fulfil these duties while we searched for a replacement and we were delighted when Richard Williams came forward to take on the appointment. We thank Harvie for all his work for the charity, particularly during the period to get the SCIO operational.

The trustees are extremely grateful to all the individuals and trusts who continue to support the charity financially.

POLYMYALGIA RHEUMATICA AND GIANT CELL ARTERITIS UK

England & Wales - Charity number 1128723

Accounts

PMR GCA UK

Polymyalgia Rheumatica
& Giant Cell Arteritis UK

Accounts
and
Annual Report
2021 - 2022

Message from Chair of trustees

The last year has seen the charity, like so many others, emerge blinking into the light of not a post-Covid but a with-Covid world. I think we probably all feel that the pressures of the pandemic have lifted, even though many of our members continue to be vulnerable, thanks to the remarkable achievements of the vaccination campaign. I also think the charity has become stronger whilst facing the challenges of the last two years.

So unapologetically I start with a tribute to our staff, our Director Candy Horsburgh and Deputy Director Fran Benson, for not only keeping the show on the road but also expanding our scope. Embracing on-line communication has kept many local groups going, and indeed enhanced the popularity and impact of the Annual General Meeting and provided well-attended webinars over the year. Our speakers at the 2021 AGM (Madeline Whitlock on the role of a specialist nurse, Chetan Mukhtyar on GCA and Justin Mason on PMR) were greatly appreciated; during the June PMRGCAuk week Vadivelu Saravanan and Georgina Ducker discussed 'PMR beyond steroids' and 'Living with GCA'; huge thanks to all of those. We have increased our membership – although we still worry we don't reach all who we might help – and these webinars have been an important driver to that.

At the group and individual level, a huge amount of work by volunteers and by my fellow trustees continues. The Helpline continues as a valuable resource, and we obtained and are very grateful for a grant from the James Tudor Foundation for Helpline Volunteer Training. Neelam Russell, our Kent Regional Organiser, has been tireless – together with our former Chair Penny Denby - in expanding activities with new groups in Dartford, Whitstable and Sevenoaks and Neelam also coordinates the Phone Friends (formerly known as the 'buddy'!) service we initiated. We have also raised support from the Sussex Community Foundation to recruit a Sussex Regional Organiser, and funds from Sevenoaks District Council, and are seeking to find local funds from other areas to expand our local support systems. We still feel our activities in some other parts of England and Wales need expanding and are seeking to do this – perhaps someone reading this will feel they can help?

We were really delighted that, thanks to a generous donation, we could make a grant for research into PMR, and we awarded the grant after a formal 'peer-review' process to Dr Max Yates and colleagues in Norfolk, for an ambitious project analysing nationwide prescribing practice to identify the true picture of steroid use in PMR. As part of the awarding process we were granted the status of non-commercial partner to NIHR, the National Institute for Health Research, which funds and co-ordinates research in the NHS in England. We look forward eagerly to the results of the research. We – and many thanks to those of our members who contributed - have also been involved in a project by Dr Sarah Mackie entitled 'PMR Voices' to identify what people with PMR feel needs to be done.

Finally, PMRGCAuk is totally dependent on our membership, and particularly on our active volunteers, to whom I and all my fellow trustees are hugely grateful.

Humphrey Hodgson
Chair of Trustees

"PMRGCAuk is an absolute lifeline with information about a condition that very few people understand."

Membership

Membership - our driving force

Our members are vital to the work we do, from shaping our services and strategy to acting as ambassadors and fundraisers for the charity.

Our membership fee is still only £15 a year and by the end of March 2022 we had 1453 members. This includes patient, friend and professional members of which 381 were new members during 2021/2022.

While members come and go as people go into remission, 26% of our membership have been with us for five years or more.

"I have recovered but I stay a member in case it comes back and so I can inform others there is light at the end of the tunnel."

"Membership is so important. Thank goodness for the expertise."

"I will continue to support the charity with my membership even if I go in to remission so I can follow the excellent work you do for people like me and I will help out where I can."

Members’ Day

Our Members’ Day and AGM 2021 took place online. Our expert speakers from the medical and research community, who all took the time to answer some of our members’ questions, were Professor Justin Mason, Dr Chetan Mukhtyar and Madeline Whitlock.

Professor Justin Mason, consultant rheumatologist and professor of vascular rheumatology within vascular sciences at Imperial College talked on “PMR and GCA – Are we making progress?”. Madeline Whitlock, Clinical Nurse Specialist (CNS) in the muscular skeletal directorate at Mid and South Essex University Hospitals Group talked about the nursing perspective of managing patients with GCA and PMR. Our final speaker was Dr Chetan Mukhtyar, consultant rheumatologist at Norfolk and Norwich Hospital and PMRGCAuk trustee. Chetan talked about steroid (prednisolone) tapering, the history of steroids and dosing, and his own Norwich Regimen plan.

Feedback from attendees:

Excellent topics covered from all three presenters.

The expertise and different viewpoints of the speakers was enlightening.

Hearing the speakers talk about their interest and commitment to helping people with PMR/GCA.

All very good but the tapering of steroids was an interesting aspect for me.

Justin Mason's presentation, quite outstanding, best speaker I've heard so far on our illnesses!

And the talk from the Clinical Nurse Specialist in which she emphasized the more personal aspects of steroid treatment eg mood changes, ways to get support, etc.

The honesty of the speakers. No posturing or hiding behind stats.

Hearing my condition discussed in a professional way that reminds me to take it seriously, and also that I still have so much to learn.

Appreciating what an excellent organisation PMRGCAuk is.
Feeling part of a well-run organisation and the speakers.

Being able to join from home and not travel a long way. The speakers were excellent and I liked the trustees' introductions. It was good to put faces to names and learn a little about them.

I enjoyed everything about Members' Day. It was a nice touch that each of the Trustees said something about themselves and their backgrounds.

To everyone at PMRGCAUK, thank you so much for your ongoing hard work and for making the Members Day so interesting and helpful.

PMRGCAuk Week 6 – 12 June 2021

PMRGCAUK WEEK

PMRGCAuk week 2021 celebrations remained online and took place in June. We were delighted to welcome our two guest speakers and more than 200 members and guests to our PMRGCAuk Week webinars.

The first talk, Living with GCA, was with Georgina Ducker, vasculitis and connective tissue disease (CTD) nurse at Norwich and Norfolk Hospital**.** Georgina spends about 60% of her time with giant cell arteritis (GCA) patients, working closely with our trustee, consultant rheumatologist Chetan Mukhtyar.

The second webinar, with Dr Vadivelu Saravanan, consultant rheumatologist at Queen Elizabeth Hospital in Gateshead, was a very comprehensive talk about steroids, covering recent PMR research which helped us to understand the challenges and importance of getting a good diagnosis and treatment as quickly as possible.

We also launched our 2022 calendar photo competition after the success of our 2021 calendar photo competition last year. This year we had over 45 entrants and 180 photos to choose from. Our 2022 calendar sold out within days, raising funds and awareness of the charity. We raised over £300 for the charity through its sales. Thank you to everyone who sent in a photo.

Thank you to all our members who gave donations for PMRGCAuk Week and for the lovely messages of thanks.

Feedback from attendees:

Excellent webinar. A lot learnt and extremely helpful thank you

Really enjoyed this webinar, very useful.

Brilliant informative talk, thank you very much

Excellent webinar. Clear and concise. Thank you so much.

Thank you - super helpful and food for thought.

Very interesting and informative, thank you.

Providing support and information

We provide support through our Telephone Helpline, our national network of Support Groups and through our online HealthUnlocked forum.

Telephone Helpline

The Helpline volunteers spoke to 403 callers from April 2021 - March 2022. The main reasons for calling are for information about PMR and/or GCA; questions and concerns about taking and reducing steroids; needing support generally with managing their condition and to talk to someone who understands through having had PMR or GCA.

Calls may last from 5 - 40 minutes each, with an average of 15- 20 minutes, depending on the need of the caller.

The helpline team consisted of six volunteers most of whom who have worked together for 4 – 5 years.

Statistics

- 74% of callers had PMR; 12% GCA; 14% had both
- The average age of callers was 71 and ¾ of callers were women
- 33% were newly diagnosed; 15% had been diagnosed less than a year; 37% had been diagnosed between 1-4 years and 8% over 5 years
- 78% of the people we speak to are first time callers and 22% of all callers have called more than once, with a small core who call several times
- 84% of calls were for information about PMR and/or GCA and at the end of their call they were either sent an information pack or directed to the website for more information
- Approximately ¾ of callers had questions or concerns about taking prednisolone and/or reducing it
- 8% of callers primarily rang to ask questions about steroid sparing medications
- 30% of callers wanted to talk about their symptoms and whether these were usual for PMR/GCA. Some of these callers felt especially unsupported with difficulty accessing their medical team or PMRGCAuk support groups. This appears to have increased since the pandemic.
- 18% of all callers are recorded as being members of PMRGCAuk

Many callers we speak to express their gratitude of being able to speak with someone who understands what it is like to have either condition and to be on steroids long term.
We aim to answer most of the calls in person, but this is not always possible and not all callers feel able to leave a message which we regret as we will always call back if invited to.

We would like to acknowledge the much-appreciated help from Stephanie Beer who every month enters the information gathered from the Helpline calls onto an Excel spreadsheet and has calculated the statistics on a monthly and yearly basis. Grateful thanks are also due to the James Tudor Foundation, without them we would not have valuable training to help us better support others while also feeling supported ourselves. A big thank you is also due to Alice Hanscomb, our expert Helpline trainer, for her patience, expertise, gentle humour and unfailing encouragement. Finally, and most importantly, our heartfelt thanks go to the wonderful Helpline team without whom the Helpline would not exist.

"I phoned for info. when I was fighting extreme lowness of spirit - but once I spoke to someone who understood - the depression lifted."

Support groups

Our Network of Support Groups provides an opportunity for people to come together, share experiences and hear from expert speakers. It's been hard for many not being able to get to meetings due to the Covid-19 pandemic and its fallout, but other members who haven't ever been able to attend groups due to health issues or not having a group nearby, were able to attend groups online via Zoom.

We have 38 Support Groups across the country and one regular Zoom support group, supporting more than 500 people every year. New Groups set up include Sevenoaks, Tonbridge & Tunbridge Wells and Ruislip. We are still working to increase the number of groups in the north of England. A number of our groups started to meet in person – either outside or in very well-ventilated spaces, though many have continued on Zoom and will continue to do so until they feel confident to meet in person. We recruited Neelam Russell (who started working for the charity in May) as our new Kent Regional Organiser, supporting groups in Kent and setting up new groups as well as spreading the word about the charity in Kent. We were also successful in securing a grant for a Sussex Regional Organiser, who will start in September 2022, and our aim is to have Regional Organisers across the country supporting all of our support groups.

Going forward it's important that we persuade those who attend meetings of the benefit of joining and becoming a member of the national charity, both for themselves and to amplify the significance of our voice in public discussions about the need for better treatment.

"The group I attend is very good. We have had excellent speakers and support from each other."
Member

*"I am pretty satisfied and appreciate others organising them when I have felt too unwell to offer to do so". **Support Group member***

*"The support groups have been a great blessing. Interacting with others and learning, getting advice from those who suffer in the same way." **Support Group member***

Neelam Russell, Kent Regional Organiser
I joined PMRGCA in May 2021, in a pilot role, as Regional Organiser for Kent. The main objective of the role was to assess the impact of having a dedicated resource to support local Group Organisers (GOs).

One of the first groups I was able to support was Whitstable who had been unable to meet for a variety of reasons. The group already had a superb venue and at the first meeting, we had a lovely volunteer who agreed to be the Group Organiser. Since then, the Group has met regularly and enjoyed a variety of sessions including seated exercise, lunches, webinars and a talk from the local Lions. Next, Dartford was set up from scratch, which involved finding a suitable venue and a willing GO. They are already meeting regularly and in May joined with another group to arrange a very successful garden centre tour and fundraiser. A new group was also started across Sevenoaks, Tonbridge and Tunbridge Wells, alternating venues, to support members travelling from different areas. We are still looking for a local GO, and so, for the moment, I continue to run that group. More recently, we have just re-started another group in Maidstone that had stopped meeting during the *pandemic and whose GO was unable to continue; we are exploring possible venues and setting up meetings to support the interests of the members attending. Summer and Christmas lunches are definitely one of our most popular events!*

I have really enjoyed the role and loved meeting so many different members from all across Kent. Although I don't have PMR and/or GCA, I have learnt so much about the debilitating condition and the extraordinary resilience of those who are living with it.

It is very exciting to see the progress in Kent and very rewarding to witness the difference the support groups make to our members. Next steps are to set up brand new groups in Kent in areas where we currently have no support, as well as continuing to support the existing groups and to hopefully see the role of Regional Organiser replicated throughout the UK.

HealthUnlocked forum

Our PMRGCAuk HealthUnlocked forum is an online patient-led community, enabling members to share their experiences and offer support. Members continue to support each other and engage with the forum on a regular forum; it is a great space not just for those newly diagnosed, but anyone who wants to share experiences and feel less alone. It is a vital and vibrant place and numbers of members continue to grow. HealthUnlocked is administrated and moderated by PMRGCAuk staff and trustees. We are very grateful for all the support we receive on HealthUnlocked, but particularly to our volunteers PMRPro, DorsetLady and Mrs Nails, whose constant work and support is invaluable to the smooth running of the forum.

At the end of March 2022 we had 4,321 active members, with on average about 230 new members signing up each month.

Quotes about the HealthUnlocked forum

“Being there to be able to answer my queries, brilliant information mainly due to there being so many who could and did offer me it to me. I was given confidence to discuss my problems with my rheumatologist, ie persuading him to allow me to use the DSNS (dead slow nearly stop) reduction of prednisolone method.”

“Without the HealthUnlocked PMRGCAuk website mine would have been a very different story. I cannot underestimate the comfort of knowing that people like the volunteers and many others are available and willing to answer questions. Most importantly they talk from the patients’ point of view and are very clear re their boundaries / when the questions must be taken to the medical practitioners. Thank you, and thank them, for all the difference that has made to me and to so many others.”

“HealthUnlocked has been a huge source of advice & reassurance & I wouldn’t have approached my rheumatologist about adrenal insufficiency if I hadn’t read about it there.”

“[HU] Forum informs me so many people are struggling in the same boat.”

Raising awareness and funds

Kent Community Foundation - £4,980 towards the administrative supplies and salary of our Kent Regional Organiser

Sussex Community Foundation - £4,864 towards the administrative supplies and salary for a Sussex Regional Organiser

Sevenoaks District Council Community Grant - £1,400 towards the salary of our Kent Regional Organiser for supporting events, people with PMR/GCA and groups in the Sevenoaks area.

James Tudor Foundation - £1,500 towards the continued training of our Helpline volunteers

Masonic Charitable Foundation awarded us £9,000 over 3 years in 2020 to set up and run our Befriending project (now called Phone Friends). We received our second £3,000 instalment in July 2021.

Tesco Bags for Help - £999.70 towards the salary of our Kent Regional Organiser

Whitstable Rotary Club donated £250 to the Whitstable Support group towards hire of hall and refreshments cost.

Southborough Lions Club donated £100 to the Southborough/Sevenoaks support group.

Christmas Card and calendar 2022 sales – we raised £1,500 from sales of Christmas cards. Thank you to Joanne Townsend, our volunteer who sent out all the Christmas cards and to Sue Barrass, who sent out the calendars.

Supporting research

- £50,000 grant towards research into PMR

In March 2021, PMRGCAuk received a very generous donation form one of our members of £50,000 for a grant towards research into PMR.

We awarded a substantial sum of this to Dr Max Yates in January 2022 to research *“Improving the quality of glucocorticoid prescribing for PMR in England”*. Currently it is recommended that patients newly diagnosed with PMR are started on higher steroid doses, and when the condition is brought under control, the dose is slowly reduced and eventually stopped. Despite these guidelines, there is wide variation in steroid prescribing for PMR. The study will look at the electronic general practice records of 23 million patient. The database is updated weekly from primary care records and includes information on patients’ diagnoses, medication, diagnostic test results and anonymised details such as age, sex, and practice location. Using this information, they will look at the prescribing patterns for patients with PMR and look at what characteristics are associated with the different patterns and how they might be mitigated.

Dr Yates and his team have started working on the project and it will be completed by December 2022.

The remainder of the grant will be awarded in 2022.

We are immensely grateful to the grant maker for their very generous grant.

PMRGCA

Annual Report and Accounts for 2021/22

Financial Review

Following two years that saw substantial surpluses due to income from a legacy and a donation to fund a research project we have had a more balanced year. In 2021/22 £38,498 of the donation was used to fund a research project with the result that we recorded an overall deficit of £32,267. A surplus of £6,231 was made on all other activities.

Income

Income for the year was £86,044 which reflects further growth in income from membership fees and general donations. Grant income totalled £15,344 including £4,980 from the Kent Community Fund and £4,864 from the Sussex Community Fund to develop and maintain the support groups in Kent and Sussex respectively. There was a small amount of income from other fundraising activities.

Expenditure

Expenditure for the year was £118,311 made up of £79,813 of operating expenditure and the £38,498 of funding for the research project. Ongoing operating expenditure increased by approximately £19,100 over 2020/21 mainly due to increased staffing levels. Expenditure on restricted funds includes the research funding, the Kent and Sussex support groups funding, helpline volunteer training and the development of the befriending project.

Balance Sheet

Total funds reduced by £32,267 to £265,558 due to the expenditure on the research project. This follows an increase of funds of £215,998 over the previous two years due to the aforementioned legacy and donation.

The trustees will continue to use these funds 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 £14,620, Restricted Reserves reduced by £36,037 and the General Reserve increased by £18,390 to £74,029 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.

Independent Examiner’s Report (to follow)

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 2022	**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 31/03/2022.

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:		**Date:**	03/09/2022
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

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	**01/04/2021**	**To**	Period end date	**31/03/2022**

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	66,421	-	-	66,421	70,328
Charitable activities	S02	1,609	15,344	-	16,953	16,591
Other trading activities	S03	2,294	-	-	2,294	1,820
Investments	S04	376	-		376	214
Separate material item of income	S05	-	-	-	-	105,919
Other	S06		-	-	-	-
Total	S07	70,700	15,344	-	86,044	194,872
Resources expended (Note 4)						
Expenditure on:						
Raising funds	S08	13,439	-	-	13,439	1,228
Charitable activities	S09	51,032	12,883	-	63,915	57,079
Separate material item of expense	S10	-	38,498	-	38,498	17,840
Other	S11	2,459	-	-	2,459	2,473
Total	S12	66,930	51,381	-	118,311	78,620
Net income/(expenditure) before tax for the reporting period	S13	3,770	- 36,037	-	- 32,267	116,252
Tax payable	S14	-	-	-	-	-
Net income/(expenditure) after tax before investment gains/(losses)	S15	3,770	- 36,037	-	- 32,267	116,252
Net gains/(losses) on investments	S16	-	-	-	-	-
Net income/(expenditure)	S17	3,770	- 36,037	-	- 32,267	116,252
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	3,770	- 36,037	-	- 32,267	116,252
Reconciliation of funds:						
Total funds brought forward	S23	199,058	98,767	-	297,825	181,573
Total funds carried forward	S24	202,828	62,730	-	265,558	297,825

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	8,101	-	-	8,101	17,241
Investments	B08	137,460	42,513	-	179,973	-
Cash at bank and in hand	B09	58,571	20,217	-	78,788	281,483
Total current assets	B10	204,132	62,730	-	266,862	298,724
Creditors: amounts falling due within one year (Note 8)	B11	1,304	-	-	1,304	899
Net current assets/(liabilities)	B12	202,828	62,730	-	265,558	297,825
Total assets less current liabilities	B13	202,828	62,730	-	265,558	297,825
Creditors: amounts falling due after one year	B14	-	-	-	-	-
Provisions for liabilities	B15	-	-	-	-	-
Total net assets or liabilities	B16	202,828	62,730	-	265,558	297,825
Funds of the Charity						
Endowment funds	B17	-			-	-
Restricted income funds (Note 9)	B18		62,730		62,730	98,767
Unrestricted funds (Note 11)	B19	202,828		-	202,828	199,058
Revaluation reserve	B20				-	
Total funds	B21	202,828	62,730	-	265,558	297,825

Signed by two trustees on behalf of all the trustees

Signature	Print Name	Date of approval dd/mm/yyyy
	Humphrey Hodgson	14/9/2022
	Geoff Holroyd	14/9/22

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 22 £	Year to 31 Mar 21 £
Membership fees	20,685	18,180
Donations	34,780	81,966
Gift Aid	7,648	20,182
	63,113	120,328
Legacies	3,308	55,919
	66,421	176,247

Membership fees and general donations have increased year on year after allowing for the single donation of £50,000 in 2020/21 to fund a research project.

4. Charitable Expenditure

	Year to 31 Mar 22 £	Year to 31 Mar 21 £
Staff costs	48,731	41,701
New website and membership systems	-	17,840
Funding of research project	38,498	-
Other costs	15,185	18,158
	102,414	77,699

5. Trustees

None of the trustees received any remuneration during the year. Trustee expenses amounted to £154 (£50 in 2020/21).

6. Employees

	Year to 31 Mar 22	Year to 31 Mar 21
Employment costs	**£**	**£**
Wages and salaries	58,502	39,420
Taxes	335	-
Pensions	1,256	2,281
	60,093	41,701

The average number of employees on a full time equivalent basis was 3.0 (2020/21 2.0).

7. Debtors

	Year to 31 Mar 22	Year to 31 Mar 21
	£	**£**
Gift Aid accrual	7,750	17,241
Investment Interest	351	-
	8,101	17,241

8. Creditors: Amounts falling due within one year

	Year to 31 Mar 22	Year to 31 Mar 21
	£	**£**
Independent Examiner's fee	600	600
Social security and pensions costs	237	199
Other creditors	467	100
	1,304	899

9. Restricted Funds

2021/22	**Balance at 01 Apr 21**	**Income**	**Expenditure**	**Balance at 31 Mar 22**
	£	**£**	**£**	**£**
Stone King Legacy	21,186		- 3,700	17,486
James Tudor Foundation	-	1,500	- 1,500	-
Garfield Weston	7,500	-	-	7,500
Wellcome Trust	5,981	-	-	5,981
Masonic Trust	100	3,000	- 3,100	-
Kent Community Foundation	4,000	4,980	- 3,955	5,025
Sussex Community Foundation	-	4,864	- 138	4,726
Tesco	-	1,000	- 490	510
Member Donation	50,000	-	- 38,498	11,502
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	98,767	15,344	- 51,381	62,730

Restricted Income

2020/21	**Balance at 01 Apr 20**	**Income**	**Expenditure**	**Balance at 31 Mar 21**
	£	**£**	**£**	**£**
Stone King Legacy	39,026	-	- 17,840	21,186
James Tudor Foundation	1,000	-	- 1,000	-
Garfield Weston	7,500	-	-	7,500
Wellcome Trust	5,981	-	-	5,981
Masonic Trust	-	3,000	- 2,900	100
Kent Community Foundation	-	4,000	-	4,000
Member Donation	-	50,000	-	50,000
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	63,507	57,000	- 21,740	98,767

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
Garfield Weston	Information packs, marketing and PR
Wellcome Trust	Roadshows outside London
Masonic Trust	Befriending project
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
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 22	31 Mar 21
	£	£
Opening Balance	143,419	100,000
Received in year	3,308	55,919
Transferred to General Reserve	- 17,928	- 12,500
Closing Balance	128,799	143,419

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 22	31 Mar 21
	£	£
Restricted Income	62,730	98,767
Legacies Reserve	128,799	143,419
General Reserve	74,029	55,639
Total Reserves	265,558	297,825

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 do not have an office. We work virtually. Our address is a mailbox. All of our staff are part time. You can rest assured that we spend every penny 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), Dorothy Byrne (Deputy Chair to August 2021), Penny Denby, Janice Maddock (Deputy Chair from September 2021), Wendy Morrison, Christine Young, Geoff Holroyd (Treasurer), Dr Chetan Mukhtyar (resigned February 2021) and Sara Muller.

Independent Examiner: Katherine Gamage from Gamages Accountancy
President: Professor Bhaskar Dasgupta
Patrons: Lord Robin Butler, Lady Wendy Levene, Dr Sarah Mackie
Staff: Candy Horsbrugh (Director), Fran Benson (Membership Secretary & Assistant Director), Neelam Russell (Kent Regional Organiser from May 2021 and Phone Friends Coordinator from October 2021) and Charon Balarabe (Administrative Assistant from November 2021).

About the charity

PMRGCAuk is the national patients' information and support charity for those with the chronic and debilitating auto-immune conditions polymyalgia rheumatica and giant cell arteritis. The two related conditions, the cause of which are currently unknown, drastically impact the quality of life of those affected - from the inability to perform everyday tasks as a result of severely restricted mobility to chronic pain, fatigue and depression. In the case of the more serious condition GCA, catastrophic blindness can occur if it is not diagnosed and treated swiftly and sadly there have been cases of some who, having lost their sight, felt so hopeless that they committed suicide. Typically affecting those over 72, around 1 in 1,000 develop PMR each year. With both conditions little known and poorly understood, PMRGCAuk is the only charity in existence dedicated to promoting knowledge and awareness amongst the public, with those diagnosed and their families, as well as raising the profile of the conditions with the medical profession.

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 and 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, particularly for the more informal meet ups.

The **Bedfordshire Support Group** met at Frosts, Willington, on the last Thursday in the month from November onwards. There are ten members and one has been off prednisolone for a year and another is now down to 0.5mg.

The **Brighton Support Group** zoomed every six to eight weeks and had a really positive time chatting to each other, having formed quite a close bond since March 2020. They contemplated a face-to-face meeting at the pub they used to meet at during 2021, but with the huge rise in Covid cases in Brighton, they postponed meeting face-to-face and continued to meet on Zoom. The group finally met face-to-face, in February and were also joined on Zoom by those who couldn't make it.

The **Cambridge Support Group** are yet to set up face-to-face meetings. When the group resumes, they hope to welcome the two new members who joined just before Covid set in.

The **Coventry Support Group** members who opted to receive them continued to receive weekly "ramblings" emails from the group organiser. These often develop into individual one-to-one emails. The group did not meet face to face during 2021/22.

The **East Midlands support group** - some members met up for coffee and other members, who have kept in touch over Zoom, might join them when they are ready. However due to the wide geographical spread of members, which makes it difficult to organise meetings. The group closed down during 2021/22 but we hope to set up some smaller groups in Derby and Nottingham.

The **Harrow/Pinner Support group** met via Zoom on monthly basis for much of the year, and generally around 11 attended the meetings. They talked about personal experiences and share local issues eg. vaccination centres, osteopaths, local Zoom talks, as well as tips and gadgets on making life easier. They finally met once again at an outside café on a lovely, sunny August day. There were six members present and they discussed meeting again in their regular hall. They devised a policy together to ensure everyone would feel safe. Nine members finally met face to face in September at their usual venue. they spent time reconnecting with each other and discussing personal experiences and updating on all things PMR and GCA. They decided not to offer refreshments but will be reviewing that for future meetings. The group met in January and discussed the different side effects of steroids and how they manage them. Over 15 different side effects were discussed and ways people try to overcome them including things to avoid – some more successful than others. They also discussed the possibility of starting a new group in nearby Ruislip.

Kent Support Groups – Whitstable, Orpington, Dartford, Maidstone and Sevenoaks, Tunbridge Wells and Tonbridge.

We are delighted to let you know that there has been lots happening throughout **Kent.** Some support groups, understandably, took things slowly as we opened up after the pandemic. Others, for example, the **Whitstable Support Group**, were able to meet up in person. They had a meeting to re-start this group and welcomed 10 members in person in late June. They had a mix of old and new members, and the group was full of ideas for future meetings. Everyone was enthusiastic and delighted to meet others who could really understand some of the challenges they have been facing. We have a new group organiser, who has already arranged several meetups including a very successful webinar. The Whitstable Support group also had a Christmas lunch for early December. In February they watched Professor Justin Mason's talk (recorded from our AGM 2021) and heard from an NHS Physio in March. The **Maidstone Support Group** kept in touch via monthly emails and phone calls since Covid began. They shared problems related to PMR and GCA and also family news, knitted chocolate orange covers for a Christmas family get together and passed on tadpoles in exchange for plant cuttings! The **Orpington Support Group**'s monthly Zoom meetings continued and they kept in touch via a WhatsApp group. Five of the group enjoyed a walk in early May. The group finally restarted their meetings in person and enjoyed a reunion after many months of being unable to meet face to face. They welcomed a new member who developed GCA during the pandemic, which had been a difficult experience for them. The group watched a recording of Professor Justin Mason's talk from the 2021 Members' Day and have appreciated being able to meet up to share their news and have been arranging to meet each other outside of the group for coffee or exercise. They continued Zoom meetings too which was open to any charity member who doesn't have a local group and would like to join in. The **Dartford Support Group** is a new group set up this year. We have a new group organiser and a venue and the support group covers Bexley, Dartford and Gravesend. The **Dartford Support Group** had a Lions Club International speaker for their March meeting who talked about their Message In a Bottle scheme (MIAB) and also donated money to the group for support in venue hire and refreshments. The first meeting of the new **Sevenoaks, Tonbridge and Tunbridge Wells Support Group** welcomed six members at the White Hart pub in Sevenoaks in January. They enjoyed a good chat with lots of ideas for future meetings. They are currently alternating venues to accommodate the wide area from which members are coming.

Southwest support groups

The support groups from **Taunton, Portishead, Bristol and Bath** met up together on Zoom every other month. When new people contacted the group, they were offered a chat on the telephone to discuss their health and advise them of the support that is available from the charity. The call is usually for about an hour. Sadly, the **Bath Support Group** group organiser had to step down for personal reasons and so far there has been no-one able to take over. There is still a big need for Bath group members to be supported and so our Southwest Coordinator and a charity member temporarily agreed to lead the meetings alternately every other month (Covid permitting). The **Truro Support Group** held an enjoyable Christmas Lunch at Truro Golf Club in December. Unfortunately, the group organiser broke her ankle in February and so the monthly meetings were put on hold.

The **Oxted Support Group** has been meeting for approximately seven years and have found a permanent home for their meetings in the local cinema which works very well: good coffee, comfy chairs and so far, quiet for everyone to hear.

The **Southend/Chelmsford Support Group** had their first face-to-face meeting in October with an attendance of 18 including four new members. Professor Dasgupta gave a very interesting and informative talk. The **Southend/Chelmsford Support Group** held a special meeting in February to remember the advances that have been made in patient services for people with PMR/GCA; to recognise the work that Professor Dasgupta has done in Southend and beyond, and to also celebrate that Southend/Chelmsford group has been running for 15 years. Eminent rheumatologists from around the world who had worked or studied with the professor submitted presentations to be shown at the meeting. Live talks were given by the professor, Madeline Whitlock, and Alwin Sebastian (who recently did his scholarship at Southend and now works in Limerick). In attendance were Hannah Padbury, who founded the Southend group, 48 group members along with the Chelmsford Mayor, Cllr. Jude Deakin and the Deputy Mayor, Cllr. Linda Mascot. Many others were also able to join via Zoom. This included representatives from PMRGCAuk, group organisers, Southend/Chelmsford group members who could not attend the meeting in person and many of the doctors who had made presentations: from the Mayo Clinic USA, Mumbai, Bangalore, Netherlands, Milan, University Hospitals in Warwickshire and Anglia Ruskin University, Chelmsford.

The **Trent Valley Support Group**. As a new group, and a small one at that, it was challenging getting Zoom meetings up and running. However, Janice Maddock (trustee) attended a couple of their initial meetings with much wanted support and they now have three new members. In June they finally met face-to-face in the group organisers garden for coffee with scones, with jam and cream. The group had a second face-to-face meeting in September at a very nice waterfront pub/restaurant, where they were happy to accommodate the group for coffee, with five members plus one husband.

The **Welwyn Garden City Support Group** continue to meet online via Zoom as many members have comorbidities and continue to feel vulnerable or do not wish to travel to meetings.

The **Worthing Support Group** met every six to eight weeks and currently have 13 members, four of whom have joined in the past this year. They met in a local café in December, but in January decided to meet via Zoom. However, most of their members prefer to meet face-to-face so met face to face from March.

The **Yorkshire Support Group** has remained meeting regularly via Zoom, and new people have joined the group. When they finally meet up in person, they will keep their Zoom meetings going too for those who are unable to travel. At the May meeting, Laura Smith of Leeds Mindfulness Co-operative ran a session on wellbeing which was extremely beneficial. They had their first face-to-face group meeting in almost two years in November. This was at the John Lewis Community Hub in Leeds and about eight people attended. One of their members kindly volunteered to meet up for an informal chat and coffee for anyone in the Kendal area. There are some who can't travel or don't yet feel it is time to meet up in a public place due to where they are in their PMR/GCA journey. In January, they hosted Dr Sarah Mackie who gave a talk via Zoom on PMR diagnosis and treatment, and her recent research, PMR Voices, that some of the Yorkshire group members had contributed to. Members and volunteers from the PMRGCAuk helpline and staff from head office attended the meeting.

The **WedPM Zoom Support Group** (an online group) meets monthly. The meeting topics follow a similar pattern to Orpington Support Group's programme. In February they had a lively discussion after watching Professor Mason's talk, and the dead slow/nearly stop steroid tapering method was circulated.

Part B – Report from PMR-GCA Scotland

I am pleased to report that 2021 saw a return to more normal activity for our charity, albeit that much of the activity was done in different ways. Our membership numbers are up and we have sent out more information packs. Our Helpline team has been busier with more one to one conversations and our Zoom meetings have given us face to face contact with members. It was heartening to be able to deliver so much in difficult circumstances.

Our most visible activity has been the Zoom meetings which were enjoyed by many members, from Ascot to Stromness, for the medical and social benefits that flow from them. We held a series of online meetings which usually took the form of a topical presentation followed by general questions and discussion. We have five local support groups which, in normal circumstances, meet regularly, monthly or bimonthly, in Aberdeen, Dundee, Glasgow, Edinburgh, and Inverness (Highland). We are also setting up a new group to operate in SW Scotland. Special mention must be made of the Dundee group which managed to squeeze in a physical meeting in November before the restrictions closed in again.

The other main objective of the charity is to promote research activities into PMR and GCA. This has been a quieter year on that front as regards activity on major projects. We have given support to grant applications for projects but not made any financial contributions so far. Our intention would be to resume a pattern of annual financial contributions. Having said that I must stress that the charity has maintained a significant level of practical involvement in research projects and studies on a range of issues. I must pay tribute to Lorna Neill who is involved with so much of that activity. Her input is highly valued by the recipients, but she is also enhancing the reputation and status of our charity.

After careful consideration by the trustees a proposal has now been implemented whereby the charity is now converting into a SCIO (a Scottish Charitable Incorporated Organisation) which is a relatively new kind of entity introduced in Scotland in 2011.

Our Secretary, Michael Benneworth, stood down in January 2022 after serving on our committee since 2013. We thank Michael for all his work for the charity and wish him well in his new activities.
Richard Cuthbert, Chair

POLYMYALGIA RHEUMATICA AND GIANT CELL ARTERITIS UK

England & Wales - Charity number 1128723

Accounts

PMR GCA UK

Polymyalgia Rheumatica
& Giant Cell Arteritis UK

Accounts
and
Annual Report

2020 – 2021

Message from Chair of trustees

A week before the period covered by this annual report the UK entered the first national lockdown; throughout the year the pandemic and the consequent restrictions and anxieties have dominated the lives of all of us. All our members have been affected, some tragically; there have been the practical difficulties of lockdown, for many the requirement to shield, and for everyone anxieties about both present and future.

And I must start by paying tribute to those who have helped the charity respond and continue to fulfil our primary aim, to support people with PMR and GCA, at this time. Our Director Candy Horsburgh, and Deputy Director Fran Benson, have been magnificent in adapting the charity's activities to cope with changing circumstances, working with group leaders, other volunteers and my fellow trustees to adapt to a world of virtual communications. New on-line meetings, webinars and WhatsApp chats, as well as the trusted favourites of the helpline and HealthUnlocked, have not only kept our work going but indeed I think I can truly say have enhanced its scope and quality.

There are many examples of this. Our September AGM could be accessed from all over the country, not only by those within easy reach of London. Presentations there, during PMRGCAuk week in June, and in other occasional webinars covered a wide variety of highly relevant topics: Dr Vanessa Quick on fast-track diagnosis for GCA, Andrew Bennett of the Dept. of Health's strategy for musculoskeletal disease, John Robson on scaling Himalayan heights to support the charity, Professor Bhaskar Dasgupta (in two talks) on PMR, GCA and Covid, Dr Sarah Muller on the long-term course of PMR, Dr Sarah Mackie on adrenal insufficiency and Dr Michael Mosley on weight loss. My huge thanks to all of those – and we know how much they were appreciated, not least from the 20% annual increase in our membership.

Other notable events have been the updating of our website https://pmrgca.org.uk, a new house-style for NewsWire and, of great importance to our continued effectiveness, successful applications to grant-giving bodies. Funds from the James Tudor Foundation, Independent Age, Masonic Charitable Foundation and Ecclesiastical's Movement for Good award and the Kent Charitable Foundation support specific projects such as training our helpline volunteers and the befriending project for the very isolated, as well as helping with the core costs of the charity. Finally, we received a very generous donation of £50,000 for us to fund research into PMR.

Sadly, I must mention the death of Keith Slater, who was of enormous help to the charity both as its Treasurer, and as a spokesman for people with GCA. We have been extremely fortunate that Geoff Holroyd volunteered to take on the role of Treasurer and has now joined the Board of Trustees.

I close with a final thank you to all the members, who are of course what it is all about, for their continued support.

With best wishes,

Humphrey Hodgson
Chair of Trustees

"PMRGCAuk is an absolute lifeline with information about a condition that very few people understand."

Membership

Membership - our driving force

Our Members are vital to the work we do, from shaping our services and strategy to acting as ambassadors and fundraisers for the charity.

Our membership fee is still only £15 a year and by the end of March 2021 we had around 1300 members, 430 of whom were new members. While members come and go as people go into remission, 48% of our membership have been with us for five years or more.

"I wish more people who come to meetings and on HealthUnlocked would become members and realise why membership is vital."

Members' Day

The annual Members' Day & AGM in September 2020 took place online. Our expert speakers from the medical and research community included Dr Vanessa Quick (Consultant Rheumatologist at Luton and Dunstable University Hospital) who talked about fast-track diagnosis for GCA; Andrew Bennett (National Clinical Director MSK conditions NHS England and Improvement) who spoke about the NHS's Musculo-skeletal's overarching vision/aim, its response and restoration strategy moving forward, linked with PMR and GCA, and John Robson (Northeast Group Organiser)talked about being on remission with PMR and climbing Annapurna IV, one of the World's Highest Mountains. Over 120 people attended the Members' Day and AGM.

"Dr Vanessa Quick was excellent. Relevant and enlightening."

"The first speaker clarified a lot of information to help me in coping with my condition."

"I enjoyed the different speakers and the variety of talks. I thought Dorothy Byrne was an excellent chair."

"Range of information supplied by speakers but also making contact with the Trustees and Charity generally."

Meeting via Zoom –
"Being able to take part for the first time."
"Being able to attend something I have been trying to do for several years."
"Being able to participate without having to travel a long distance."

"Even if you have a physical meeting could we have an online link please?"

"Good that you organized the AGM via Zoom so that many more of us could attend."

PMRGCAuk Week 7 – 13 June 2020

PMRGCAUK WEEK

PMRGCAuk week moved online, as most events did this year, for some of our events. As members were unable to meet up to raise money through coffee mornings, sponsored event or quiz nights, we set up 2 online webinars. One was with our president, Professor Bhaskar Dasgupta on “PMR and GCA: The Road Beyond Covid”; the other by our trustee Dr Sara Muller on “The Study of the course of PMR, 2 years after diagnosis.” Over 300 people attended the webinars.

We also launched our 2021 calendar photo competition with the theme of “Lockdown”. Many photos were sent in and as hard as it was to choose the 13 winners (yes, 13 we needed a photo for the front cover too!) our first PMRGCAuk calendar was created and we raised over £300 for the charity through its sales. Thank you to everyone who sent in a photo.

“Thanks for letting me know that my photo had been chosen for the 2021 calendar. The news really made my day special. Now I'm looking forward to seeing my photo in print & the other pictures that were chosen too.” ***Barbara, member***

“Many thanks to the Professor for his clear and helpful presentation - and his willingness to answer questions.” ***Marge, member***

“Thanks Sara - for today and for the hard work setting up the study. All very helpful and fascinating.” ***Member***

EVENTS and FUNDRAISING EVENTS PROGRAMME

Our fundraising event programme continued into 2020 and onwards with webinars by TVs Dr Michael Mosley on a healthy diet, and our patron Dr Sarah Mackie on adrenal insufficiency and another by our President Professor Bhaskar Dasgupta on Covid: An immune response gone wrong.

"Thank you, Dr Mackie. Very informative and well-presented I have some useful information from this thank you so much”. ***Yvonne, member***

“Prof Dasgupta, brilliant talk - thank you! So well-illustrated - who would have thought of using the 4 horsemen of the Apocalypse!” ***Rosemary, member***

Providing support and information

We provide support through our Telephone Helpline, our national network of Support Groups and through our online HealthUnlocked forum.

Telephone Helpline

The Helpline volunteers spoke to an average of 30 callers a month from April 2020 - March 2021. The main reasons for calling are for information about PMR and GCA from the newly diagnosed; questions and concerns about taking and reducing steroids and needing support by speaking to someone who understands their concerns.
Calls may last from 5 minutes to 50 mins each depending on the need of the caller.

The helpline team currently consists of seven volunteers currently giving up their time to answer helpline calls. It is estimated that, between us, we spend between 15 – 20 hours per month on speaking to Helpline callers.

Statistics
The Helpline volunteers spoke to 350 callers during the year April 2020 – March 2021

- 72% had PMR; 14% GCA; 14% had both
- The average age of callers was 75 and 2/3 of callers were women
- 20% were newly diagnosed; 20% had been diagnosed less than a year; 39% had been diagnosed between 1-4 years and 11% over 5 years
- 50% of the people we speak to are first time callers and 30% of all callers have called more than once, with a small core who call several times.
- 55% of callers requested information about PMR and/or GCA and were either sent an information pack or directed to the website for more information
- Over half of callers had questions or concerns about prednisolone and/or reducing it
- 10% callers asked questions about steroid sparing medications
- 23% of callers wanted to talk about their symptoms and if they were usual for PMR /GCA, some being distressed and / or feeling unsupported by their medical team.
- Between 1% - 2% of callers had lost some sight
- Just 11% of all callers are members

Most callers we speak to express their gratitude of being able to speak with someone who understands what it is like to have either condition and to be on steroids in the long term.

We aim to answer most of the calls in person, but this is not always possible and not all callers feel able to leave a message. This is identified on the system as a “missed call” – during this time period, an average of two calls a week were missed.
.
We would like to acknowledge the much-appreciated help from Stephanie Beer who every month enters the information gathered from the Helpline calls onto an Excel spreadsheet and has calculated the statistics on a monthly and yearly basis. Grateful thanks are also due to the James Tudor Foundation, without them we would not have valuable training to help us better support others while also feeling supported ourselves. A big thank you is also due to Alice Hanscomb, our expert Helpline trainer, for her patience, expertise, gentle humour and unfailing encouragement. Finally, and most importantly, our heartfelt thanks go to the wonderful Helpline team without whom the Helpline would not exist.

Support and Meet up groups

Our Network of Support Groups provides an opportunity for people to come together, share experiences and hear from expert speakers. It's been hard for many not being able to get to meetings due to the Covid-19 pandemic, but other members who haven't ever been able to attend groups due to health issues or not having a group nearby, were able to attend groups online via Zoom.

We have 38 Support Groups across the country, supporting more than 500 people every year. New Groups set up include Trent Valley and our Ilkley Support Group changed its name to Yorkshire Support Group. We are still working to increase the number of groups in the north of England. The current Covid-19 pandemic postponed "in-person" meetings, and many groups moved online to video conferencing meetings such as Zoom. Some of our Support Groups have not taken their meetings online to Zoom, and other groups have welcomed members from these groups to their Zoom meetings. Going forward it's important that we persuade those who attend meetings of the benefit of joining and becoming a member of the national charity, both for themselves and to amplify the significance of our voice in public discussions about the need for better treatment.

"I found purpose and structure after having to give up work and being on my own at home. The support group and the charity were a lifeline to the future."
Member

"It is now seven years since I was diagnosed with PMR and two years ago found PMRGCAuk and through them discovered the support groups.

Very reluctantly I decided to join the East Midlands Derby group and went along with my husband to a meeting. After a few meetings I realised there was nothing for people in my immediate area and with the blessing of Bridget Towning, who organised the East Midlands group, decided to try to organise something more central to Burton upon Trent, Lichfield and Tamworth - now the "Trent Valley Group". What I hadn't factored into the plan was LOCK DOWN. However, with the help of Bridget and the support and encouragement of Candy at PMRGCAuk we went ahead and I became a "Zoomer" as this was the only way of meeting. The problem was that I'm sure like many groups, only a few members were familiar with Zoom and as we were only a few (6 members) it was difficult. I did get great support from trustee Janice Maddock, who at our first meeting swelled the numbers by 50% as there were only two of us.

What I do try to do is email everyone in the group, following a meeting to update them on anything we may have discussed or any PMRGCAuk news.
We were finally able to get together face to face on 17th June, but the problem was still where to meet, as local cafes were getting very crowded and meeting rooms not yet open, so our garden seemed the best option and was very successful, with good weather and three new members, including one lady's husband. From personal experience I do feel it's a good idea to welcome partners, so that it helps them get a clear and sympathetic understanding of PMR and GCA.

So now the plan is to try to meet again face to face in September at a cafe or meeting hall. It hasn't been easy due to lock down, but hopefully the emails have kept us together, if only to ask how everyone is and offer support if required."

Dorothy Waterhouse, Group Organiser Trent Valley

HealthUnlocked forum

Our PMRGCAuk HealthUnlocked forum is an online patient-led community, enabling members to share their experiences and offer support. Members continue to support each other and engage with the forum on a regular forum; it is a great space not just for those newly diagnosed, but anyone who wants to share experiences and feel less alone. It is a vital and vibrant place and numbers of members continue to grow. HealthUnlocked is administrated and moderated by PMRGCAuk staff and trustees.

It has given me support when needed. So good to know that there are many more people than I imagined living with these conditions and getting on with their lives.
HU Member

PMRGCAUK was a valuable starting point for information and using HealthUnlocked has been valuable to me especially at a point when after three years into PMR I was struggling to cope. Reading others experiences definitely helped."
HU Member

"By being able to access the forum anytime and reading different views/ideas. Also, the humour, it's not all doom & gloom, thank goodness. Being able to let off steam without being judged."
HU Member

"HealthUnlocked has been a huge source of support & reassurance & I wouldn't have approached my rheumatologist about adrenal insufficiency if I hadn't read about it there."
HU Member

Raising awareness and funds

- Independent Age grant - £7,488 towards core costs.
- We received the final amount of our legacy from our late member Joan Binns, £55,909.
- Members and supporters successfully voted for the charity to receive another £1,000 from the Ecclesiasticals' Movement for Good grant.
- Sales of our lockdown calendar 2021 and our Christmas cards raised over £1,300.
- The Masonic Charitable Foundation awarded us £9,000 over 3 years to set up and run our Befriending project (we received our first £3,000 instalment in July 2020).
- We received £4,000 from the Kent Community Foundation to support the salary costs of our Kent Regional Organiser, whose role is to support all Group Organisers in Kent, and to set up new groups in the county.
- St Martin's Challenge awarded the charity a £500 bursary.
- The City of London's Portsoken Ward Club chose us again to be their charity of the year, chosen by Judi Sanders, Master of the Portsoken Ward Club.

Supporting research

- £50,000 grant towards research into PMR

In March 2021, PMRGCAuk received a very generous donation form one of our members of £50,000 for a grant towards research into PMR.

We invited applications from clinicians and/or scientists to address one or more of the research priorities identified by people with polymyalgia rheumatica – pain; stiffness and fatigue; diagnosis; steroid management and self- management as discussed in Morton et al – Clin Rheumatol 2019: 38(6); 1767-1772 Applicants needed to be affiliated to a UK University and/or NHS hospital.

There will be a two-stage application process:

Stage 1 Preliminary application. Applicants submitted a single page of A4 (minimum font size 11), identifying the research question to be answered; methods to be used; how the success of the project will be determined; how results of the research might be applied; previous research history of the applicant(s); and budgetary outline.

A shortlist of applicants will be made from whom a Stage 2 application will be requested, to be judged by a peer-review process. At this stage, applicants will be asked to include a 5-page research proposal, including a lay summary, a detailed budget, evidence of institutional support, and justification for the research in respect of priorities for public health, the NHS, and/or social care.

The successful candidate will be informed of the result by January 2022.

We are immensely grateful to the grant maker for their very generous grant.

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	Polymyalgia Rheumatica and Giant Cell Arteritis UK		
On accounts for the year ended	31st March 2021	**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 31/03/2021q.

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:**	07/08/2021
Name:	Mrs Katherine Gamage ACMA MAAT		
Relevant professional qualification(s) or body (if any):	Associate Member of the Chartered Institute of Management Accountants (ACMA, CGMA). Member of the Association of Accounting Technicians (MAAT)		
Address:	8 Pemscott Close Alvescot Oxfordshire, OX18 2AA		

CHARITY COMMISSION
FOR ENGLAND AND WALES

PMRGCAuk		Charity No (if any)	1128723
		Company No	6763889
Annual accounts for the period			
Period start date	01/04/2020	To	Period end date 31/03/2021

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	70,328	-	-	70,328	39,667
Charitable activities	S02	9,591	7,000	-	16,591	14,658
Other trading activities	S03	1,820	-	-	1,820	257
Investments	S04	214	-		214	23
Separate material item of income	S05	55,919	50,000	-	105,919	105,000
Other	S06	-	-	-	-	-
Total	S07	137,872	57,000	-	194,872	159,605
Resources expended (Note 4)						
Expenditure on:						
Raising funds	S08	1,228	-	-	1,228	1,478
Charitable activities	S09	53,179	3,900	-	57,079	50,541
Separate material item of expense	S10	-	17,840	-	17,840	7,840
Other	S11	2,473	-	-	2,473	-
Total	S12	56,880	21,740	-	78,620	59,859
Net income/(expenditure) before tax for the reporting period	S13	80,992	35,260	-	116,252	99,746
Tax payable	S14	-	-	-	-	-
Net income/(expenditure) after tax before investment gains/(losses)	S15	80,992	35,260	-	116,252	99,746
Net gains/(losses) on investments	S16	-	-	-	-	-
Net income/(expenditure)	S17	80,992	35,260	-	116,252	99,746
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	80,992	35,260	-	116,252	99,746
Reconciliation of funds:						
Total funds brought forward	S23	118,066	63,507	-	181,573	81,827
Total funds carried forward	S24	199,058	98,767	-	297,825	181,573

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	17,241	-	-	17,241	2,978
Investments	B08	-	-	-	-	-
Cash at bank and in hand	B09	182,716	98,767	-	281,483	180,846
Total current assets	B10	199,957	98,767	-	298,724	183,824
Creditors: amounts falling due within one year (Note 8)	B11	899	-	-	899	2,251
Net current assets/(liabilities)	B12	199,058	98,767	-	297,825	181,573
Total assets less current liabilities	B13	199,058	98,767	-	297,825	181,573
Creditors: amounts falling due after one year	B14	-	-	-	-	-
Provisions for liabilities	B15	-	-	-	-	-
Total net assets or liabilities	B16	199,058	98,767	-	297,825	181,573
Funds of the Charity						
Endowment funds	B17	-			-	-
Restricted income funds (Note 9)	B18		98,767		98,767	63,507
Unrestricted funds (Note 11)	B19	199,058		-	199,058	118,066
Revaluation reserve	B20				-	
Total funds	B21	199,058	98,767	-	297,825	181,573

Signed by two trustees on behalf of all the trustees

Signature	Print Name	Date of approval dd/mm/yyyy
	Humphrey Hodgson	07/10/2021
G Holroyd	Geoff Holroyd	07.10.2021

Financial Review

Income

Income for the year was £194,872 boosted by the balance of a legacy donation of £55,919 and a generous donation of £50,000 by one member to fund a research project. Grant income totalled £15,988 and there was a healthy growth in income from increased membership and general donations. However, there was little income from fundraising activities due to the impact of Covid 19.

Expenditure

Expenditure for the year was £78,620 including one-off costs of £17,840 for the completion of the new website and the membership system software. Expenditure from restricted funds includes the £17,840 for the new website and membership software with the balance spent on staff training and the development of the Buddy project.

Balance Sheet

Total funds increased by £116,252 to a total of £297,825 in large part due to the generous donations of £55,919 from the legacy and £50,000 to fund a research project. This follows an increase of funds of £99,746 last year which was primarily due to the first instalment from the same legacy of £105,000.

Over the two years the total funds have increased by £215,998 which places the charity in a healthy financial position. The trustees will continue to use these funds and future income to support the needs of its members and to develop the services for its members in a sustainable way as well as funding the research project referred to earlier.

Reserves analysis

Following the introduction of the legacy reserves policy the charity’s total reserve of £297,825 is made of restricted funds of £98,767 (which includes the £50,000 towards a research project), £143,419 in the legacies reserve and a general reserve of £55,639 in line 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 has been introduced with effect from 01 April 2020.

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 31/03/2021	**Year to 31/03/2020**
	£	**£**
Membership fees	18,180	13,636
Donations	81,966	23,053
Gift Aid	20,182	2,978
	120,328	39,667
Legacies	55,919	105,000
	176,247	144,667

Donations in 2020/21 include a single donation of £50,000 specifically to fund a research project. The amounts shown as legacies represent one legacy which was received in two parts across two financial years.

4. Charitable Expenditure

	Year to 31/03/2021	Year to 31/03/2020
	£	£
Staff costs	41,701	36,712
New website and membership systems	17,840	7,840
Other costs	18,158	13,829
	77,699	58,381

5. Trustees

None of the trustees received any remuneration during the year, but expenditure of £50 was reimbursed to one trustee.

6. Employees

	Year to 31/03/2021	Year to 31/03/2020
Employment costs	£	£
Wages and salaries	39,420	36,079
Pensions	2,281	633
	41,701	36,712
The average number of employees during the year was	2	2

The average number of employees on a full-time equivalent basis was 1.3 (2020 1.3).

7. Debtors

	Year to 31/03/2021	Year to 31/03/2020
	£	£
Gift Aid accrual	17,241	2,978

8. Creditors: Amounts falling due within one year

	Year to 31/03/2021	Year to 31/03/2020
	£	£
Independent Examiner's fee	600	600
Social security and pensions costs	199	756
Other creditors	100	895
	899	2,251

9. Restricted Funds

2020/21	Balance at	Income	Expenditure	Balance at
	01/04/2020			31/03/2021
	£	£	£	£
Stone King Legacy	39,026	-	- 17,840	21,186
James Tudor Foundation	1,000	-	- 1,000	-
Garfield Weston	7,500	-	-	7,500
Wellcome Trust	5,981	-	-	5,981
Masonic Trust	-	3,000	- 2,900	100
Kent Community Foundation	-	4,000	-	4,000
Member Donation	-	50,000	-	50,000
Amalgamation with North East PMRGCA	10,000	-	-	10,000
	63,507	57,000	- 21,740	98,767

2019/20	Balance at	Income	Expenditure	Balance at
	01/04/2019			31/03/2020
	£	£	£	£
Stone King Legacy	46,866	-	- 7,840	39,026
James Tudor Foundation	-	1,000	-	1,000
Garfield Weston	-	7,500	-	7,500
Wellcome Trust	5,981	-	-	5,981
Amalgamation with North East PMRGCA	10,000	-		10,000
	62,847	8,500	- 7,840	63,507

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
Garfield Weston	Information packs, marketing and PR
Wellcome Trust	Roadshows outside London
Masonic Trust	Buddy project
Kent Community Foundation	To create additional support groups in the Kent region
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
	31/03/2021	31/03/2020
	£	£
Opening Balance	100,000	-
Received in year	55,919	105,000
Transferred to General Reserve	- 12,500	- 5,000
Closing Balance	143,419	100,000

In 2019 the charity received £105,000 as part payment of a legacy, the second payment being received in 2021. Due to the size of this legacy in relation to the charity’s existing reserves the Directors established a Legacies Reserve policy which has been applied as shown in the table.

11. Reserves Summary

	Year to 31 Mar 21	Year to 31 Mar 20
	£	£
Restricted Income	98,767	63,507
Legacies Reserve	143,419	100,000
General Reserve	55,639	18,066
Total Reserves	297,825	181,573

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 do not have an office. We work virtually. Our address is a mailbox. We only have the equivalent to just over one member of staff. You can rest assured that we spend every penny 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), Dorothy Byrne (Deputy Chair), Penny Denby, Janice Maddock (interim Treasurer July to September 2020), Wendy Morrison, Christine Young, Keith Slater (Treasurer to July 2020), Geoff Holroyd (Treasurer from September 2020), Dr Chetan Mukhtyar and Sara Muller.

Independent Examiner: Katherine Gamage from Gamages Accountancy
President: Professor Bhaskar Dasgupta
Patrons: Lord Robin Butler, Lady Wendy Levene, Dr Sarah Mackie
Staff: Candy Horsbrugh (Director), Fran Benson (Membership Secretary & Assistant Director).

About the charity

PMRGCAuk is the national patients' information and support charity for those with the chronic and debilitating auto-immune conditions polymyalgia rheumatica and giant cell arteritis. The two related conditions, the cause of which are currently unknown, drastically impact the quality of life of those affected - from the inability to perform everyday tasks as a result of severely restricted mobility to chronic pain, fatigue and depression. In the case of the more serious condition GCA, catastrophic blindness can occur if it is not diagnosed and treated swiftly and sadly there have been cases of some who, having lost their sight, felt so hopeless that they committed suicide. Typically affecting those over 72, around 1 in 1,000 develop PMR each year. With both conditions little known and poorly understood, PMRGCAuk is the only charity in existence dedicated to promoting knowledge and awareness amongst the public, with those diagnosed and their families, as well as raising the profile of the conditions with the medical profession.

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 and meet up 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 discussion groups
● Publish a members' magazine three times per year and send regular email updates
● Maintain an up-to-date website and improved social media presence
● 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, particularly for the more informal meet ups.

Bath Support Group
Unfortunately, owing to the pandemic it has not been possible for the Bath Group to meet in person. The Group Organiser has stayed in touch with the group by email, both passing on news from the charity and also answering questions. Several group members have taken part in the regional Zoom support meetings organised by Wendy Morrison, the SW/Taunton Group Organiser, which they have found beneficial. One member who was feeling very isolated and down during the winter lockdown asked virtually if any other members were willing to provide regular support by phone. Those who responded to this appeal have become supportive friends. In addition, the Group Organiser made occasional phone calls to members who cannot be contacted by email.

Bedfordshire Support Group
We have had no meetings at all during this financial year but we do, occasionally, chat on WhatsApp.

Brighton Support Group
The Brighton group have kept in touch throughout the pandemic with Zoom meetings every six to eight weeks. We have really valued these and have got to know much more about each other, whilst supporting one another. We are hoping that when we can meet up again face to face, it will be possible to Zoom those who cannot physically be there, which will be especially useful to one of our members who has moved three hundred miles away!

East Anglia Support Group
Due to Covid 19 our group hasn't been able to meet up.

East Midlands Support Group
The East Midlands support group members have kept in touch by email and phone. Additionally, a small group have had Zoom meetings every few months. A small group have also met at outside cafes for informal get togethers.

Harrow/Pinner Support Group
Since all group activities were postponed in April 2020 due to the Coronavirus pandemic and lockdown, any important information to share was done so via email. In November 2020, our Coordinator stood down due to ill health. Our trustee Janice Maddock agreed to take over as Interim Coordinator until someone else took over to make sure the group did not fold.

Since December 2020 interested members of the Harrow/Pinner Group have continued to 'meet' on Zoom on a monthly basis. Everyone is invited each time but there is a core group of 11 who attend. We have been able to talk about our personal experiences, but we have also been able to share 'local' issues e .g. vaccination centres, osteopaths, local Zoom talks as well as tips and gadgets on making life easier. We also discussed things we were looking forward to when lockdown eases which ranged from cuddling grandchildren, going to the hairdressers and eating out. Members are also updated on any news from PMRGCAuk e.g. the new website, webinars and PMRGCAuk Week and are also contacted via email.

The group is eager to meet up again as soon as we are able to and Janice has been in contact with the Church Hall and has acquired their Covid guidelines.

Maidstone Support Group

Maidstone Group hasn't been doing anything as a group, but all members are communicated with on a monthly basis via email, and usually they have several replies to each of the monthly emails.

North East Group

The last 12 months have been very quiet for the North East (NE) Support Group due to the national restrictions. For several months we maintained regular correspondence via email and a few phone calls to NE members. I created a virtual climbing expedition in the Himalayas, similar to a Monty Python spoof, and sent regular updates on progress made on the virtual climb and a few photographs. This went down really well and feedback was excellent with people getting worried if I had not provided an update. I received a lot of more support and feedback than a normal expedition!

There were regular updates and weekly quizzes over the period April to August, and again this seemed to go down well with all recipients. Members eagerly awaited the answers to the weekly quiz and on a few occasions contacted me to discuss the answers. This seemed to be very good for morale as we were all locked down.

We attempted to establish Zoom meetings but the response from members was not forthcoming, so we continued with monthly updates via email.

Orpington Support Group

Like most groups round the country the Orpington support group has been unable to meet properly since March 2020. Early on we established a Zoom support group and this still runs monthly, usually on the 4th Wednesday. We invited anyone, anywhere to join us. As support groups round the country set up their own Zoom meetings our members became those who live mainly in Kent and Sussex but not exclusively - Marilyn who moved from Maine to Idaho in the US and is a regular attendee. We have shared information on our vaccination experiences, eating out (mostly not eating out!), hobbies and new interests as well as supporting some of our group who have had to live through other serious medical conditions made more challenging because of the Covid situation.

Since the start of 2021 our numbers have reduced but the dozen or so who continue to meet have become a very special group of people. It is difficult to remember that most of us have never met in person as we now know each other well! Although meetings have continued throughout there has been a downside. Members who were unable to embrace the Zoom technology have missed so much and we have missed meeting them. We have included them throughout on emails and also created a WhatsApp group.

What of our extended group members? We intend to continue the Zoom support meetings too so long as they are needed. One possibility is that with the new technology we have all become more used to we may be able to include the Zoomers in our ‘real’ meetings. Better still we hope that some of the Zoom group members in Sussex might even set up their own meetings now they have all become friends.

Oxted Support Group

The Oxted Support group has been very quiet. They have tried meeting in the local park and started to have a few Zoom meetings, however they fizzled out after a while.

Plymouth Support Group

Hopes for the Plymouth Group to meet up were dashed by the Covid restrictions during the 2020/21 year. Some of our members participated in Zoom meetings arranged by PMRGCAuk and South West Region, covering a variety of subjects.

SW Support Groups

Bath (see above for more details), Bristol, Plymouth (see above for more details), Portishead, Salisbury, Taunton, Torbay, Truro.

This year has been very different for the Groups as unfortunately due to Covid 19 we have been unable to meet face to face. This has therefore been a challenge to support our local members. Throughout the year we have been holding support groups using zoom. Unfortunately, many of our members have not been able to embrace the technology and therefore those attending are substantially less than would normally attend. This has meant we can only signpost others to the alternative services offered by the charity including the Helpline, our website, HealthUnlocked and communication with the individual leaders via email.

Also, during the year some volunteers have needed to step down either permanently or temporarily and we would like to give our sincere thanks for their service and best wishes to them all. During the year we were pleased to welcome two new group organisers in Portishead and we are now looking forward to organising their first face to face meeting. Indeed, we are all looking forward to actually meeting again and the leaders have already been thinking and planning how this can be done safely and make everyone feel relaxed in a supportive atmosphere again.

Welwyn Garden City Support Group

It seems a lifetime ago when our support group was set up in late 2019 and then, suddenly, in April 2020 we were faced with finding an alternative to face to face meetings as the pandemic took hold. Remember those days?

Being a fairly new group, we had hardly established ourselves, but having got used to Zoom for other purposes, it seemed the best way to still meet those members who were able and wanted to meet in this way. The unfortunate side of that was a decline in numbers and although I offered to help any of them set up Zoom and talk them through using it, only a few joined me online. We had been holding actual meetings every two months but decided that virtual meetings would take place once a month.

I kept in touch with everyone by email and sometimes by phone, letting them know when there would a relevant webinar given by the charity and I know that those who were members found these very informative and helpful. On one occasion in November 2020, my Rheumatology Consultant, Dr Thiraupathy Marianayagam, who works for the Northeast Hertfordshire NHS Trust, kindly gave a talk to our members online and the Shropshire group were invited to attend. A very satisfying number of eighteen joined in the meeting and Dr Marianayagam answered many questions after her talk.

Since then, we have continued online monthly, apart from the odd hiccough. As we proceed down the road to understanding further the effects of this virus and how to mitigate its impact, the future is still uncertain for many vulnerable members of society, so we watch and wait for a more sustainable way of living.

Yorkshire Support Group

Yorkshire Support Group has been established now for 4 years supporting people with PMR or GCA. The group has two meet up venues in Yorkshire comprising, Ilkley and Leeds. Due to a year of Covid we did not meet face to face. Group members did embrace the new technology of Zoom online virtual meetings which broke the cycle of being alone when not able to go out due to the lockdown situation affecting the nation. Those unable to Zoom were updated by email on current events and offered one to one support by email if required. Activities such as the excellent webinars put on by the charity were promoted through the group email and ensured distribution of information on PMR and CGA was given either on the Zoom platform or a summary in email.

All members were ensured continuity of support this year even though people could not get together physically. An average of 9 people attended each meeting out of 52 members we have registered on the mailing list. Zoom has made meetings accessible for people who did not live nearby and encouraged a few national members to join the group.

Part B - Report from PMR-GCA Scotland

In common with the rest of the UK the main feature of our activity in the last year has been the lack of in person meetings. Thankfully, the Zoom facility has allowed group contact online and these gatherings have been remarkably successful. They have replicated the warmth of a physical gathering and allowed us to deliver the medical and social benefits that are at the core of our aims. Our support groups are based in the five main cities of Scotland so the online activity allowed us to welcome members who cannot normally attend – we had attendees from Orkney, Cowal, the Borders and England. It will be a challenge to maintain this spread of participation when we try to revive traditional meetings. Our other point of direct contact is the Helpline which has continued to function as a valuable source of support and information, particularly for newly diagnosed patients.

Our Annual Meeting for 2021 had to be an online affair but still proved to be a success. Two excellent speakers provided valuable information, particularly regarding Fast Track services for GCA. Membership numbers remain fairly constant at about 290 predominantly living in Scotland. Initial approaches tend to be via the Helpline or website and we would love to increase awareness amongst health professionals who could inform patients of our existence and activities.

We have remained active in the more medical spheres of interest. We awarded a grant to support research work at Edinburgh University into new imaging techniques for diagnosing Large Vessel Vasculitis. This aims to give a more accurate assessment of disease activity allowing a tailored approach to treatment. Our involvement with various research projects and committees continues, largely through the dedicated efforts of Lorna Neil. The benefits of meeting in person are missed but meeting online keeps things moving. Although most of the content was over my head, I was impressed by one meeting where attendees were based right round the World from Canada, Europe, Australia and elsewhere.

As always, we appreciate and give thanks for the work done by all on the Trustee Committee, the Helpline volunteers and local group organisers.