



**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 basis; 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 from 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.



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:

Katherine Gamage

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	Restricted income funds	Endowment funds	Total funds	Prior year funds
		£ F01	£ F02	£ F03	£ F04	£ 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

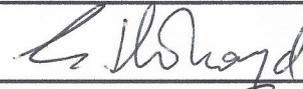
Section B

Balance sheet

Guidance Notes

	Unrestricted funds	Restricted income funds	Endowment funds	Total this year	Total last year
	£	£	£	£	£
	F01	F02	F03	F04	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
	Geoff Holroyd	07/10/2021

PMRGCA Annual Report and Accounts for 2020/21

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 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
	31/03/2021	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 01/04/2020	Income	Expenditure	Balance at 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 01/04/2019	Income	Expenditure	Balance at 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 31/03/2021	Year to 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 Gamage 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 be 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 Thirupathy 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 hiccup. 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.