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").

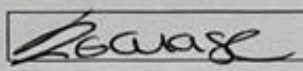
I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 31 Mar 22	Year to 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 31 Mar 22	Year to 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