

Annual Report and Accounts

of
Polymyalgia Rheumatica and Giant Cell
Arteritis UK

PMRGCAuk

for the Year Ended

31 March 2017

Dated
9th September 2017



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1. Reference and Administrative Details of the Charity

Name of Charity: Polymyalgia Rheumatica and Giant Cell Arteritis UK

Acronym: 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

Current Trustee/Directors

Dorothy Byrne, Deputy Chair

Penny Denby, Chair

Lady Wendy Levene

Dr Sarah Mackie

Janice Maddock

Wendy Morrison

Christine Young

Honorary Treasurer (April 2017 onwards): Andrew Osborne

President: Professor Bhaskar Dasgupta

Patron: Lord Robin Butler

Trustee/Directors who retired during this year

Kate Gilbert

Robin Hamilton, Treasurer

Bank Details: HSBC, 13 Parliament St, York.

Independent Examiner: Basil J Taylor FCA

2. Structure, Governance and Management

The charity's governing document is its Memorandum and Articles of Association, which together form the constitution. The charity is a company limited by guarantee, which incorporated on 2nd December 2008, and became a registered charity in March 2009. The constitution designates the methods to be adopted for the appointment of new trustee/directors who together form the charity's governing body, the board of trustees. Policy decisions are taken by the trustee/directors as a collective at quarterly board meetings. Penny Denby is chair of trustees with Dorothy Byrne as deputy chair.

During the year, trustee Kate Gilbert and trustee/treasurer Robin Hamilton retired from the board. We would like to take this opportunity to thank them very much for their contribution as trustees, and are very pleased that Kate continues her involvement with the charity as project lead for the Rheuma Research Roadshow. This year we welcomed Janice Maddock to the trustee board and since the end of the year, Andrew Osborne has succeeded Robin Hamilton as treasurer. Finally, Mark Howell will soon be joining the board.

This year the charity was able to expand and create the new post of Outreach Coordinator. Our paid staff team now comprises of Director Kathryn Busby (2.5 days per week), Membership Secretary Laurene Brooks (1 day per week), Outreach Coordinator Claire Jones (2 days per week), and two freelance staff, Bookkeeper Anne Hulbert

and Rheuma Research Roadshow project lead Kate Gilbert. In addition to the paid staff, we are very fortunate to have dozens of committed and talented volunteers across the country, without whom our work would not be possible. Volunteers run the charity's groups and telephone helpline, moderate and respond to forum posts, carry out vital and time-consuming administrative work, organise press and media coverage, represent the charity at talks and events and much, much more.

PMRGCAuk works in collaboration with several other organisations toward the fulfilment of its aims and objectives. These other organisations include Arthritis and Musculoskeletal Alliance (ARMA), British Society for Rheumatology (BSR), Royal National Institute for Blind People (RNIB), British Health Professionals in Rheumatology (BHPR), Arthritis Research UK, Fight for Sight, European League against Rheumatism (EULAR), Birmingham Arthritis Resource Centre, Vasculitis UK and Arthritis Care. It works in partnership with two other independent charities dedicated to PMR and GCA, PMR-GCA UK North East Support, and PMR & GCA Scotland (see Appendix: Reports from Support Groups and Associate Charities).

3. Funds held as Custodian Trustee

There were no funds held as custodian trustee on behalf of others.

4. Public Benefit Statement

The charity believes that the board of trustee/directors have complied with their duty with regard to the Charity Commission guidance on public benefit. The aims and objects of the charity in relation to public benefit can be seen under item 5. Evidence of this compliance can be seen under item 6.

5. Objectives and Activities

5.1 The Charity's Objects:

- 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.

5.2 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 personal 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 social media presence
- Distribute information leaflets 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 Ministers, members of the House of Lords 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

- Run the Rheuma Research Roadshow, supported by the Wellcome Trust
- 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

6. Achievements and Performance

A message from the Chair of Trustees, Penny Denby

Polymyalgia Rheumatica & Giant Cell Arteritis UK continues to achieve so much. We remain a very small UK national charity but the annual report shows how much can be accomplished by so few.

It is now over two years since I joined the board and I would like personally to thank everyone involved for their wonderful and continued enthusiasm and effort. Everyone involved – the board, staff and volunteers – generously give many hours each year to ensure that the voice of PMRGCAuk is heard by more and that everyone affected by PMR and GCA can find the support they need.

Thank you to:

- Our volunteers who set up and run Meet ups and Support Groups and to the members who help them. The number of groups has grown significantly... there are now more than thirty opportunities for people to meet others close to where they live thanks to you. We need more of you!
- Our team of Helpline volunteers - always there at the end of the phone ready to listen to callers when they are feeling depressed, lonely and unsure. We need more of you too!
- Those who moderate our Health Unlocked forum and contribute to the peer support offered there.
- Our distribution team – especially Rob in Lincolnshire who has single-handedly mailed information packs almost daily this year, and sent out more than 1,500 *NewsWires* during the past 12 months.
- Justine Rawlins, whose amazing success with PR on our behalf has brought PMR and GCA to the attention of millions of people in the UK.
- Rob Lawrie for being our official photographer at events and providing many of the wonderful images you see in *NewsWire*.
- Sandra Isitt for her innovation and skills in developing the steroid taper web application.
- Angela Loftus for her wonderful work moderating our first RNIB assisted phone forum.
- Marjorie Bailey for her diligent and meticulous assistance with proof reading.
- All our volunteers who help with tasks including website updating, supporting at events and more.
- 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.

Thank you also to:

- Our Director, Kathryn Busby, whose knowledge and efficiency is the reason the charity's cogs turn smoothly. How she fits all that she does into 2.5 days I don't know! As the charity grows Kathryn's workload has expanded hugely.
- Laurene Brooks, Membership Secretary, whose workload has also grown considerably over the past two years as membership has doubled.
- Claire Jones, Outreach Coordinator, who has organised help and information for support groups round the country and the first pilot for the PMRGCAuk Phone Forum.
- Kate Gilbert who has organised and run the hugely successful Rheuma Road Shows which have brought medical professionals and patients together and spread the word of PMR and GCA to many more.
- Robin Hamilton for his time as a trustee and Treasurer and to Andrew Osborne for taking over the role of Treasurer in April 2017.
- Our President Professor Bhaskar Dasgupta and Patron Lord Robin Butler for their wonderful support.

And finally, thank you to:

- My fellow trustees. Being a volunteer trustee of any charity is a very special job. PMRGCAuk trustees are busy people but they still find time to do that little bit extra which is needed to increase the charity's reach to the public and within the medical sector. Your trustees are a great, inspirational and dependable team.

Almost ten years ago, on 10 March 2008, 25 people attended the inaugural meeting of PMRGCAuk. Since then the charity has grown with many more people round the UK now involved in raising awareness and providing support. I ask you now to consider joining this fantastic team. Offering to help your local group organiser, fundraising amongst your friends and family, speaking to people in your community about PMR and GCA, volunteering to help at events or offering your services as a trustee will truly make a difference. At every level we need to build the PMRGCAuk team so we can continue and expand the excellent work of the charity and support more and more people.

Best wishes



Review of the year

We provide information and support to people with PMR and GCA

- This year our thirteen **support groups** met on a regular basis across the country, with a range of informal discussions and formal events with expert speakers. For a taste of what has been happening across the country in individual groups, please see appendix 2.

97% of members who expressed an opinion agreed that they found it helpful to meet others with the same condition in support and meet up groups. 97% agreed that guest speakers in group meetings give

useful information. 90% agreed that being part of the group helps them to feel more in control of their treatment. 93% agreed that being part of the group helped them to manage their condition.¹

- Following last year's successful pilot of four small, monthly **meet up groups** in Kent, we have expanded across the country and now have seventeen groups. These meet ups are smaller and less formal than support groups, they meet in free venues like cafes or pubs and so can be more easily set up. We hope that they will enable more people with PMR and GCA to join a group near to their home and get together with others who understand what they're going through.

"Joining the Orpington group has been very valuable for me. Being able to share information and learn from others is both reassuring and provides real guidance."

In our 2017 members' survey, 50% of respondents who did not currently attend a group told us that this was due to not having a meeting near enough to them. We will continue to work hard in the coming year to support the sustainable growth of the network.

"I was so pleased to find a support group, as I felt as though I was the only person who had PMR/GCA!"

- This year we also carried out a short initial pilot of **telephone meet ups** in partnership with RNIB. These meet ups are particularly intended for those who are unable to attend a group in person, for example because they live in a remote location or for health reasons. 43% of respondents in our 2017 survey indicated that they would be interested in telephone support groups if they were available. We are now evaluating the initial pilot and will be making improvements prior to rolling out the second stage in 2017/2018.
- Our national **helpline service** is delivered by volunteers providing emotional and practical support. While the helpline does not offer medical/clinical advice, it is an invaluable service that allows people to discuss their illness and is particularly helpful for those who feel isolated and afraid after receiving their diagnosis, or want to see if what they are experiencing is 'normal'. Many callers request information about PMR and GCA having been recently diagnosed, others wish to talk about reducing prednisolone successfully, some need reassurance about various symptoms they are experiencing.

100% of members who expressed an opinion agreed that the person they spoke to on the helpline was helpful and a good listener. 98% agreed that the person they spoke to was knowledgeable and they received useful information during the call. 97% agreed that they felt less anxious after the call.²

- The **helpline** volunteers continue to speak to an increasing number of callers now averaging 50 people per month. This tends to peak after newspaper articles or television coverage which highlights PMR, GCA and the charity. Most calls come through during office hours but the helpline also receives a small number of calls in the evening and at weekends. There are currently six volunteers giving up their time to answer calls. The volunteers have experience of one or both conditions and taking steroids themselves, or direct experience of caring for someone with PMR or GCA.

¹ The description of "agreed" in this and all survey statistics in this report includes all respondents who chose 'agree' or 'strongly agree' in answer to the question. Those who answered 'not applicable / don't know' were not included in these calculations. For the full results please see www.pmrgca.co.uk/content/survey2017

² Ibid.

- Volunteer Sandra Isitt has been developing and testing an innovative **steroid taper web application** which will be launched next year.
- The PMRGCAuk **HealthUnlocked forum** is an online community, enabling patients to share their experiences and provide peer support. It is particularly helpful for people who cannot get to a support group, or prefer online discussion to telephone support. It is moderated by PMRGCAuk volunteers. By the end of the year, the forum had 4,671 active members.

95% of members who expressed an opinion agreed that the forum helps them to feel less alone with their condition. 94% agreed they felt better equipped to ask the right questions when they see their doctor and 96% agreed it helps them to feel more in control of their treatment and helps them to manage their condition.³

- **Membership** links the charity to the people it serves. We ended the year with almost 800 active members, an increase of 30% from the end of last year. Our members receive *NewsWire* magazine, regular email updates and are invited to attend the annual Members' Day and AGM. In 2016-17 our volunteer Rob posted an average of 30 information packs each month to people who have been newly diagnosed with PMR and GCA, this has approximately doubled from the previous year.
- The **2016 Members' Day and AGM** was attended by more than 70 people and in addition to small group discussions and plenty of time to meet fellow members, the event featured three guest speakers: Professor Bhaskar Dasgupta (a leading expert in GCA), Dr Kate Gilbert (author of *PMR & GCA: a survival guide*) and Dr Saleyha Ahsan (A&E doctor and presenter of *Trust me, I'm A Doctor*).

"As wife to a sufferer, meeting others and hearing their testimonies has raised my awareness and given me more insight and sympathy."

"Excellent, informative day."

"Outstandingly good AGM and Members' Day. Thank you."

We raise awareness within the public domain, medical profession and government

- In February 2017, BBC2's flagship health programme, ***Trust Me, I'm a Doctor***, featured an item on GCA, the needless sight loss caused by poor diagnosis and treatment, and the benefits of a fast track system for patients. The item included footage filmed at our 2016 Members' Day and interviews with some of our members, as well as featuring the new fast track pathway for GCA pioneered by our President Professor Bhaskar Dasgupta and his team at Southend University Hospital.
- This year we have seen a big increase in our **press coverage**; this is thanks to Justine Rawlins, an expert in health sector PR who is generously volunteering her time and skills to support us. As well as helping to ensure sell-out audiences by promoting our Rheuma Research Roadshows in the local press, Justine is achieving significant national coverage. In January 2017, the Mail on Sunday – which has a circulation of 1.2 million – ran a piece on PMR/GCA and recent trials of tocilizumab as an alternative treatment. In

³ The description of "agreed" in this and all survey statistics in this report includes all respondents who chose 'agree' or 'strongly agree' in answer to the question. Those who answered 'not applicable / don't know' were not included in these calculations. For the full results please see www.pmr-gca.co.uk/content/survey2017

March 2017 the Daily Express published 'Why a stiff neck could leave you blind' featuring trustee Janice Maddock's PMR story after she was diagnosed in 2013 at the age of 55.

Pain, aching and stiffness that made simple everyday tasks impossible became a way of life for Janice. Her symptoms began in 2012 and, initially, she put the physical aches and pains down to the stress of caring for her elderly mother, who had passed away in the September of that year. It took six months before she was diagnosed, by which time her symptoms had become so bad, she was unable to get in and out of bed and could not turn her head, which made driving dangerous. PMR was the main reason why Janice took early retirement from her job as a Childcare Development Advisor.

"Everyday life was very difficult – I used to dread going to bed as it was so painful getting in and out and I used to have to park away from other cars as I had so much difficulty getting in and out. The final straw was when I couldn't even bend down to put my shoes on and my husband had to do it for me."

"When I was diagnosed with PMR, I was immediately put on a high dose of steroids which reduced the pain and stiffness but had side effects. I was very tired and put on weight because they made me so hungry. I reduced my steroids but did this too quickly as my symptoms started to come back. I had a bit of a meltdown as I thought I was never going to get better. It was at this point that I found out about the charity PMRGCAuk, who were brilliant at offering me advice and support."

"Looking back, my mum must have had PMR as she had all the symptoms. She had a lot of physical problems and was quite disabled and had to have a lot of care, but that was down to PMR. It makes me really sad to think that she suffered. As part of my role with PMRGCAuk I now give talks to community nurses and carers and very few of them have even heard about the conditions. More needs to be done to educate these groups as they are often the ones who will be caring for patients who may develop PMR and GCA."

Read the rest of Janice's story at www.pmrgca.co.uk/news/stiffneck/

- In October 2016, one hundred guests enjoyed afternoon tea in the **House of Lords**, arranged by Lady Levene as a fundraising event for the charity. Our guest speaker, charity Patron Lord Butler, recounted his extraordinary civil service career working closely with Edward Heath, Harold Wilson, Margaret Thatcher, John Major and Tony Blair and the event raised more than £10,000 – by far our largest fundraising event to date.
- Charity representatives attended the **BSR Rheumatology Conference** in Birmingham this year and rheumatologists, researchers, nurses and physiotherapists were among those who visited our stand to order information resources and find out how PMRGCAuk could help their patients. We continue to keep those who requested to be updated informed about the charity.
- We have continued this year to campaign for **fast track diagnosis of GCA** to be adopted and implemented in all areas of the NHS. We have had exceptional support from the charity's President Professor Bhaskar Dasgupta and staunch supporter Lord Michael Wills.
- A series of **awareness-raising talks** has begun in Hillingdon, aimed at people over 50 and those who work with them. Trustee Janice Maddock has spoken to 121 people so far, including members of the public and professionals such as Lead District Nurses and Community Matrons. From a show of hands at each event we estimate that only around 10% of people had previously heard of PMR or GCA – following

the talk, they all can recognise the symptoms. This programme will continue and we plan to expand it as Janice shares her experience with other members who want to speak in their local communities.

- **Website** visitor numbers have grown significantly during this year, thanks to Carla Forder from Fandango Digital, who kindly gave her time to set up free Google Ads for the charity, ensuring that more people who need us can find us. Unique visitors increased from 26,000 in 2015-2016 to 68,000 in 2016-2017. In the coming year we plan to develop and improve the content available. The charity **Facebook** page continues to grow with an increase of 22% this year reaching 2646 likes and our **Twitter** account has increased its following by 39% to 667; through Twitter we connect with the medical profession and other organisations working in the same field.

96% of those who expressed an opinion agreed that the PMRGCAuk website was easy to navigate around and 92% agreed that they found what they were looking for. 95% agreed they would go back to the website again if they needed more information.⁴

We support and promote research into PMR and GCA

- The **Rheuma Research Roadshow** project, funded by a grant from the Wellcome Trust's Engaging Science programme, aims to raise the public's knowledge of medical research that is relevant to PMR and GCA. It is designed in three stages: stage 1 is a series of 'research roadshows' around the country, visiting major centres of research and inviting researchers to share their work with an audience of patients, partners and carers, and sometimes, healthcare workers; stage 2 takes the roadshows to major treatment centres; and stage 3 will collate material collected to contribute to an educational programme for GPs and other health workers.
- Following the successful grant bid, the project launched in October 2016 with a period of planning. By the end of March 2017 four roadshow events in Stage 1 had been held, in Southend, Bristol, Keele and Leeds. All were very successful, with a 95% 'high' satisfaction rating from audiences. The Southend roadshow focused on innovative work with the GCA fast track and new treatments on the horizon, Bristol's focus was 'the patient experience', Keele's was 'what is happening in primary care?' and Leeds focused on 'what is going on in the body?' Since the start of the new financial year, three more roadshows have been held and the rest are in the planning stages. Audiences have ranged in size from 35 to 75. The project is being monitored and evaluated with the help of an advisory group made up of clinical researchers, rheumatologists and patient representatives.
- Members of PMRGCAuk have been invited to participate in a number of **research projects** during the year. Additionally, in order to start the process of approval of tocilizumab for the treatment of new cases of GCA, NICE brought an invited group together, including representatives from PMRGCAuk, to discuss the scoping of the approval work. This will be followed in the coming months by a consultation process to which various stakeholders will be invited to contribute.
- Letters of support for **research bids** have been given this year to the University of Sheffield for development of a Patient Reported Outcome Measure for Polymyalgia Rheumatica (PMR) and to Keele

⁴ The description of "agreed" in this and all survey statistics in this report includes all respondents who chose 'agree' or 'strongly agree' in answer to the question. Those who answered 'not applicable / don't know' were not included in these calculations. For the full results please see www.pmr-gca.co.uk/content/survey2017

University for understanding the longitudinal experience of people with polymyalgia rheumatica and giant cell arteritis.

7. 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. Our special thanks go to the Wellcome Trust for supporting the Rheuma Research Roadshow. Finally we would like to thank our members, whose interest and support makes our work relevant and worthwhile and whose feedback drives us to improve and ensure we provide the services that are most needed.

8. Treasurer's Finance Report for PMRGCAuk Accounts to March 2017

The charity has had a very satisfactory financial year. This report should be read in conjunction with the accounts to Year End 31st March 2017 in Appendix 1 together with the Examiner's Report.

Income

Income was £64,429, of which £20,872 was a grant from Wellcome Trust for a specific project, the Rheuma Research Roadshow. The balance income was £43,557, which was considerably more than 2016 (£30,605). Subscriptions and donations exceeded 2016. One very large contributor were special fundraising events arranged by Lady Levene; these raised £12,654 against £3,891 in 2016. The visit to the House of Lords to listen to Lord Butler over a lovely tea by the riverside was very special. The staff and trustees continue to work on ideas for raising funds in future.

Expenditure

Expenditure was £49,694 compared to 2016 £28,726, of which £11,131 was spent from restricted funds, leaving the balance as £38,563. This was satisfactory in the light of the increased income of the charity. The main increases were in the money spent on charitable activities, which include the helpline, *NewsWire* magazine and help to support groups.

Claire Jones was employed by the Charity to specifically assist with the growth and running of Support Groups around the country. Her salary has been partly paid from two donations given last year specifically for that purpose. Also Kate Gilbert has been contracted to lead the Rheuma Research Roadshow, funded by Wellcome Trust. £5,152 has been spent this year out of £20,872 from the full grant, which is also a restricted fund.

Net Movement in Funds

The net movement in funds for the year is £14,735 against £1,879 last year. However £9,741 of this surplus is in restricted funds leaving £4,994 in the general fund. This is more than satisfactory and it is good to see more being spent on charitable activities, which is very much in line with the constitution of the charity.

Balance Sheet

The charity has £46,164 in funds carried forward, split between £30,173 in general funds and £15,991 in restricted funds. Cash funds are £47,283 and are split with £30,498 general funds and £16,785 in restricted funds. Trustees will give serious consideration to spending some more of the cash surplus on the charitable activities in the future, while maintaining a cash reserve in line with charity policy and Charity Commission guidance.

Appendix 1: Accounts and Examiner's Report

Independent examiner's report to the trustees of PMR GCA UK, a Charitable Company (the Company)

I report on the accounts of the Company for the year ended 31 March 2017, which are set out on pages 13 – 14.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) but that, as the Company's Gross Income exceeded £25,000, an independent examination is needed.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act;
- and to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
 - a. to keep accounting records in accordance with section 386 of the Companies Act 2006; and
 - b. to prepare accounts which accord with the accounting records, comply with the accounting requirements of section 396 of the Companies Act 2006; and
 - c. with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 have not been met; or
- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Name: Basil J Taylor FCA
B J Taylor, Chartered Accountant
Address: "Dobbies", Itchenor, West Sussex, PO20 7AA
Date: 9th September 2017



PMR GCA UK			Charity No (if any)	1128723
Annual accounts for the period				
Period start date	1.4.2106	To	31.3.2017	

Section A Statement of financial activities

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	29,520	20,872	-	50,392	26,655
Charitable activities	S02	12,654	-	-	12,654	3,891
Other trading activities	S03	1,373	-	-	1,373	49
Investments	S04	9	-	-	9	10
Separate material item of income	S05	-	-	-	-	-
Other	S06	-	-	-	-	-
Total	S07	43,557	20,872	-	64,429	30,605
Resources expended (Note 6)						
Expenditure on:						
Raising funds	S08	12,048	-	-	12,048	6,156
Charitable activities	S09	16,180	10,587	-	26,767	13,679
Separate material item of expense	S10	10,334	544	-	10,878	8,892
Other	S11	-	-	-	-	-
Total	S12	38,563	11,131	-	49,694	28,726
Net income/(expenditure) before investment gains/(losses)	S13	4,994	9,741	-	14,735	1,879
Net gains/(losses) on investments	S14	-	-	-	-	-
Net income/(expenditure) Extraordinary items	S15	4,994	9,741	-	14,735	1,879
Transfers between funds	S16	-	-	-	-	-
Other recognised gains/(losses):	S17	-	-	-	-	-
Gains and losses on revaluation of fixed assets for the charity's own use	S18	-	-	-	-	-
Other gains/(losses)	S19	-	-	-	-	-
Net movement in funds	S20	4,994	9,741	-	14,735	1,879
Reconciliation of funds:						
Total funds brought forward	S21	25,179	6,250	-	31,429	29,550
Total funds carried forward	S22	30,173	15,991	-	46,164	31,429

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	(Note 15)	B01	-	-	-	-	-
Tangible assets	(Note 14)	B02	-	-	-	-	-
Heritage assets	(Note 16)	B03	-	-	-	-	-
Investments	(Note 17)	B04	-	-	-	-	-
	<i>Total fixed assets</i>	B05	-	-	-	-	-
Current assets							
Stocks	(Note 18)	B06	-	-	-	-	90
Debtors	(Note 19)	B07	1,770	-	-	1,770	2,083
Investments	(Note 17.4)	B08	-	-	-	-	-
Cash at bank and in hand	(Note 24)	B09	30,498	16,785	-	47,283	30,859
	<i>Total current assets</i>	B10	32,269	16,785	-	49,054	33,032
Creditors: amounts falling due within one year	(Note 20)	B11	2,890	-	-	2,890	1,603
	<i>Net current assets/(liabilities)</i>	B12	29,379	16,785	-	46,164	31,429
	<i>Total assets less current liabilities</i>	B13	29,379	16,785	-	46,164	31,429
Creditors: amounts falling due after one year	(Note 20)	B14	-	-	-	-	-
Provisions for liabilities		B15	-	-	-	-	-
	<i>Total net assets or liabilities</i>	B16	29,379	16,785	-	46,164	31,429
Funds of the Charity							
Endowment funds	(Note 27)	B17	-	-	-	-	-
Restricted income funds	(Note 27)	B18	-	15,991	-	15,991	6,250
Unrestricted funds		B19	30,173	-	-	30,173	25,179
Revaluation reserve		B20	-	-	-	-	-
	<i>Total funds</i>	B21	30,173	15,991	-	46,164	31,429

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval dd/mm/yyyy

Appendix 2: Reports from local support groups, meet ups and associate charities

Support Groups and Meet Ups

Barnet Meet Up

Our first meeting in March went well and was followed by a second in June. Both meetings were well received by those present, with everyone contributing to the discussion, and a further meet up is planned for the end of September. There have been several new enquiries and the future looks bright for the new group.

Derek White

Cambridge Support Group

We had a good year with three very interesting talks. The first was by rheumatologist Natasha Jordan from Addenbrooke's, who talked to us about living with PMR and how to learn to say NO and take care of yourself. We found it a really useful talk and many of us came away having learned new ways in how to say NO without offending others! Our second talk of the year was from Diabetes UK and was really informative. Our third and final talk was actually the Rheuma Roadshow hosted by Kate Gilbert. It was a great afternoon and we came away with a lot of knowledge we did not have previously. Thank you to Kate and the team for all of their hard work and input.

Our valiant walking group, led by Sue Myring, continued with their monthly walks and were enjoyed by all who attended. Our monthly coffee groups also continued and we had a good year with people coming and going and chatting about all sorts of topics including PMR and GCA and supporting one another. Trisha Rumsby is now running the monthly coffee get-togethers.

I have stepped down after five years as Group Organiser and wish everyone well in their journeys. I am hoping someone can be found to take the group on. My personal thanks to all those at PMRGCAuk for your support during these past five years and I look forward to seeing the national organisation grow and develop.

Dale Hodgson

Coventry Meet Up

The Coventry Meet Up Group is usually attended by seven to ten members. Most of us live outside Coventry, travelling from Leicestershire, Warwickshire, the West Midlands and Worcestershire. We welcome any new members who care to join us, even for a one-off visit prior to setting up a group in their own locality.

Our group is very friendly and we particularly value the opportunity that the meetings give us, to support and encourage each other. We no longer feel so isolated, as we face the challenges of PMR and GCA.

Ann Hollingsworth

PMR-GCA Support East Anglia

The PMR-GCA Support East Anglia group continues successfully with three meetings a year. As members arrive they enjoy refreshments and the opportunity to share their experiences with others before listening to the

speaker. At the AGM in April 2016, members moved around to sit with others living in the same vicinity and this resulted in Members' Informal Get-Togethers being organised, which are still continuing between the more formal meetings with a speaker. The very small Norwich group which had been meeting for about two years grew in numbers and other gatherings were formed in Stowmarket and Woodbridge as well as four members living in the same village near Bury St Edmunds making contact with each other.

In July 2016 a speaker from the Medicines and Healthcare products Regulatory Agency (MHRA) Yellow Card Scheme came to speak and in October 2016 Dr Richard Watts, consultant rheumatologist at Ipswich Hospital and senior lecturer at Norwich Medical School attended. After Dr Watts' visit the committee decided to recommend for members' approval at the 2017 AGM donating a sum of money to him for a research project he and his colleagues plan to undertake later in the year. Members are always pleased to co-operate in research projects and a good number completed the questionnaire for a project funded by the North-East group in autumn 2016.

About six weeks before each meeting members always receive a newsletter, prepared by the Chairman, giving details of future speakers and any relevant news including anything available from PMRGCAuk. Overall it has been a successful year with all meetings held at the usual venue, Needham Market Community Centre.

Maryan Fidler

Kent Support Groups & Meet Ups

We have five groups now - Hastings, Maidstone, Orpington, Oxted and Sevenoaks. These are accessible to people in Kent and we are also delighted when visitors from further afield can join us. Orpington and Maidstone are both in a period of transition as they have moved venues which allow them to host speakers. In Orpington we have had a talk from the chair of the local Lions Club about their 'message in a bottle' scheme and have a number of speakers planned for the next few months. A physiotherapist who teaches clinical pilates (from which a number of group members have benefited) and an optician (who is aware of GCA) are booked for September and October. We also hope to finalise dates for a practice nurse from a local surgery and a rheumatology nurse from the local hospital. In Maidstone a local pharmacist will be the first speaker. We are trying to coordinate the speaker dates so that people can attend from wherever they are in Kent.

We have two lotteries set up by local councils to support Kent people. Tonbridge and Malling have been running for 6 months. Anyone buying a £1 ticket through a link on the PMRGCAuk website can win up to £25,000 and 50p of the £1 comes directly to the local groups.

Penny Denby

London Support Group

The London Group met four times during the year. Our speakers have included Dr Richard Campbell, consultant rheumatologist from the King's College NHS Trust talking about the drugs we have to live with, Amanda Ursell, a writer, journalist, consultant and nutritionist who spoke about how what we eat and drink can affect us, and Liam Rodgers from a physio practice in London called 'Ten' who led a session on what physiotherapy can do for us and why we should keep moving as much as we can – even if it's only a few steps a day. We don't have speakers for our summer meetings, but hold group discussions instead and in 2016 we discussed living with our conditions.

Anne Storey

Peterborough Support Group

Peterborough currently has 53 contacts listed. Situated on the edge of the Fens, the group attracts people from a wide area across the East Midlands including Lincolnshire, Bedfordshire, Nottinghamshire, Norfolk, Hertfordshire, North Cambridgeshire, Huntingdon, Rutland Buckinghamshire, Derbyshire and this year, even as far north as South Yorkshire.

One of the key issues for people in our group is being able to share personal experience with others who really understand what living with PMR and GCA means. Our informal 'coffee and chat meetings', continue to provide an ideal, friendly setting for crucial peer support and are consistently well attended by local people in the group. For those people who find the journey to Peterborough too far, we keep in touch by email and try to arrange car sharing where possible. People are now swapping numbers with each other for additional peer support in between 'meet ups' and this year have been encouraging others to keep active and mobile by sharing information about their own personal interests, hobbies and activity groups.

There have been two general meetings this year including the AGM. Our guest speakers have included

- Annabel Kingsbury, a physiotherapist who gave a comprehensive talk on the importance of movement, including some practical exercises for strength and mobility, together with a relaxation session.
- Rita Bali, a pharmacist and the Executive Development Officer for Cambridgeshire and Peterborough Local Pharmaceutical Committee, who explained the role of pharmacists in the community and answered questions about medication.

This year some of our group have volunteered through Peterborough Hospital Rheumatology department to take part in a study looking at clinical and immunogenetic characterisation of GCA and PMR, run by Professor Ann Morgan. Members have also taken part in a study into how PMR/GCA might impact on hearing, and volunteered as patients for training local medical practitioners in their ultra sound training.

To increase publicity we have requested that all GP surgeries, hospital rheumatology departments, public libraries other public venues display our group publicity material. The Peterborough Council for Voluntary Service directory for all voluntary and statutory organisations now includes our details and meetings are featured in the local newspaper.

Clare Marshall

PMRGCAuk South West

This year has seen our reach within the South West expand considerably and it seems as if this expansion is going to continue into the next financial year. This only goes to highlight just how many people in our area suffer from these debilitating conditions and how much our support is valued, particularly at a time when the NHS is very over-stretched.

During February, Wendy Morrison attended a Muscular Skeletal Symposium held in Taunton which was providing training for GPs, nurses, physiotherapists and occupational therapists. There was a session on PMR and GCA, and Wendy staffed a stand providing supportive educational literature. She also attended a meeting of the Vasculitis Group at the Royal Devon and Exeter Hospital and was able to talk to rheumatologists from Exeter and Torquay about our support groups.

Taunton Support Group

In Taunton we met 11 times during the year. When we had no speaker, we met at the Harvester situated near the motorway junction, for relaxed conversation, information and self-help. Dr Samy Zakout a consultant rheumatologist from Weston General Hospital came and spoke in May. Samy worked with Professor Kirwan at the Bristol Royal Infirmary running a Rapid Access Clinic for PMR and GCA, and has been involved in research into the conditions. In July, Laura Carpenter a medical herbalist joined us; she has a keen interest in the use of traditional remedies that can be harvested from the hedgerows and included references to herbs which have anti-inflammatory properties. November was the annual visit of Teresa Jewell, the lead rheumatology specialist nurse from Musgrove Park Hospital. Teresa is a firm favourite guest as she is always prepared and happy to answer all our questions. February saw the second visit of Susana Gomes, a pharmacist from Boots Chemists. She was back by special request as we all gained so much information from her first visit.

Plymouth and Cornwall Support Group

Unfortunately, due to ill health, Sally and Derek who ran the Plymouth group found it necessary to step down. We can't thank them enough for all their work. Much of the year the group has therefore been led by Wendy Morrison with local help from Yvonne Godfrey. Due to a publicity drive in the local press early in 2017 many more people are now attending the meetings and a local team of leaders is now in place led by Keith Bulley. The new team are now looking forward to a speaker meeting and a musical fundraising evening.

Bath Cafe Meet Up Group

We have been meeting monthly for just over a year now offering each other mutual support and a listening ear. Topics of general interest have been steroid reductions and how to get the most out of your ten minute GP appointment. As regular readers will remember, from our photo in the spring 2017 edition of Newswire, we had a very sociable Christmas Lunch which helped everyone to get to know each other better. We also met up for a chat and a snack lunch before going as a group to the informative Bristol Roadshow.

Salisbury Meet Up

Salisbury group has been going exactly one year since Penny came down to the launch in June 2016. From an initial core of 8 people, we now have about 20 members, although an average meeting has more like 8 to 10 attendees. We have more than a fair share of GCA sufferers, also many younger members, just into their 50's and quite a good sprinkling of men! One of our members Liz Mitchell has just raised over £700 for PMRGCAuk by doing a 10 mile walk in the New Forrest. We are all very proud of Liz who is still recovering from a bad spell of GCA, well done Liz!

Torbay Meet Up

Torbay group meet at The Ness in Shaldon. The first meeting was held in July and was led by Trish Galli. Again the numbers are increasing as more local people find the group and they also are attracting an ideal number to their meetings benefiting from the support provided by Trish.

We are hoping that in next year's report we will also be mentioning groups in Bristol and Cornwall.

This work is not possible without our volunteers and I would like to thank all our new and existing volunteers for their invaluable contribution. We are of course not able to set up more groups until volunteers in an area come forward. We are also looking for additional volunteers in Taunton to help run the support group there. Please get in touch if you are able to help by emailing pmrgca.southwest@yahoo.co.uk

Wendy Morrison, with reports from Patrick O'Donnell (Salisbury) and Patricia Martin (Bath)

Southend Support Group

When Hannah Padbury retired as support group organiser in 2016 unfortunately there was no-one to take over the support group in Southend. Fortunately, following first Rheuma Research Roadshow in Southend in February, member, Pat Fedi, volunteered to take on the role. Madeline Whitlock, clinical nurse specialist rheumatology from Southend Hospital offered to assist with the group meetings.

We are looking forward to the first meeting of the new group which will take place on Thursday, 26 October 2017 when Madeline will be running a question and answer session for all who attend.

Penny Denby

Surrey Support Group

The Surrey group is now into its seventh year, with current registered membership standing at 63, and with twelve of those members having joined us in the last 12 months. Average attendance at each meeting is between 30 and 40. During the reporting year, the group experienced the sad passing of two of its long-standing and regular members, who have since been sorely missed at our meetings. At the start of 2017, meetings of the group moved from our original council-owned venue to the nearby function room of a leisure centre, with the latter being far more accommodating and suited to our needs.

During the year, the group again welcomed some interesting and informative guest speakers. The highlight of the year was a return visit by guest speaker, Dr Rod Hughes, consultant rheumatologist at St Peter's Hospital, and mentor to the group. This meeting saw our highest ever attendance where 62 members, partners and carers joined us to hear this ever-popular speaker talk about the long term effects of PMR and treatment.

Ragnar Domstad, a past sufferer of PMR and GCA, came all the way from Sweden to provide us with a fascinating slide show presentation on a method he had initiated some years ago for reducing steroid dosages more successfully after having experienced repeated flares with previous attempts at reducing. This method, and variations of it, have since been tried and proved successful by many people diagnosed with PMR and/or GCA, with it fondly becoming known as the Ragnar Method. It is basically a slowly, slowly tapering approach to reducing steroids, particularly at the low doses of 5mg and below. At the same meeting, we were delighted to welcome back Eileen Harrison (Physiology, St Andrews), a Medical Science Translator and PMR Patient Representative from Italy, whose holiday in the UK had coincided with the date of Surrey's August meeting. Eileen is well-known to many PMR/GCA patients through her informative and helpful contributions to several PMR online forums, including that organised by PMRGCAuk on the HealthUnlocked site.

Other guest speakers during the year included a consultant immunologist from St George's Hospital, London, who gave a very interesting talk entitled 'Blood Tests – the Magic and the Mystery'. Another regular and popular speaker at several of our meetings during the year was a rheumatology researcher from St Peter's Hospital, Chertsey, who invited members with present or past GCA to take part in a retrospective study designed to find out more about the causes of giant cell arteritis and polymyalgia rheumatica and whether it may be possible to predict whether a person with one of these conditions will be more severely or only mildly affected.

As organiser of the group, I managed to locate about a dozen volunteers, including a couple of members of the Sussex group, who have thus far participated in the study which has involved just one hospital visit to provide a small volume of blood. The lead site for the study is University of Leeds. The rheumatology researcher is also a

qualified yoga instructor and has treated the group to sessions on practical breathing and relaxation, and on the subject of mindfulness.

This well established and very friendly group now looks forward to another year of getting together in support of each other in order to share experiences with these pesky conditions, whilst learning from each other how best to manage them, and from further guest speakers, with one of our first of the next reporting year being a local pharmacist.

Shirley O'Connell

Wales Support Group – Cardiff Meet Up

The first meeting of the Wales support group was held in Cardiff in November. I volunteered to help set up the group as I was very disappointed to find there was no group in Wales, as other parts of the UK are well-represented. Our first meeting was surprisingly well-attended; we were expecting only a few people, but in fact we had about fifteen. Wendy Morrison from the national charity gave us some information about the illnesses, the charity and the support groups, but she emphasised that the group is ours, to run as we wish.

We have had regular meetings this year, every two to three months, always in Cardiff, as it is easily accessible. Indeed, some people travel quite long distances to them. The total number of people attending each meeting has remained about the same, but each time there are new people, which is a good sign. The meetings are informal, we chat about our problems, exchange information, and hopefully learn something. However, we are going to try something new for our next meeting and have a speaker, perhaps this will attract a wider audience. We will wait and see the outcome of this new venture, and then decide how to conduct future gatherings.

Sue Smith

Associate charities

PMR-GCA Scotland

Registered Scottish Charity No. SC037780

As always the charity put its main efforts in 2016/17 into support for members through the groups, the helpline and the website. By the end of 2016 a number of new volunteers from all over the country were attending trustees' meetings and helping with tasks which enabled the charity's voice to be heard in a greater number of situations, such as the Scottish Health Council's "Our Voice" meeting in Glasgow in December, Angus Health Fair in September and other conferences organised by the Health and Social Care Alliance, of which we are a member.

At our AGM in April 2016, Dr Neil Basu from Aberdeen and Dr Kumar Vinod from Dundee gave presentations on Vasculitis-related Fatigue and Tayside Pathways for Diagnosis and Treatment of GCA respectively. Bea Nicholson as Chair organised a conference in Glasgow in September, with the purpose of introducing Fast Track and the new Guidelines for GCA to medical professionals in Greater Glasgow and Clyde. Professor Baskhar Dasgupta and Clinical Nurse Specialist Madeline Whitlock from Southend were the speakers and received a very positive response from the sixty or so medical professionals who attended. This continues to be followed up wherever possible, particularly during our regular participation in the Cross Party Group (CPG) on Arthritis and Musculo-Skeletal Conditions in the Scottish Parliament at Holyrood.

In February 2017 we linked up with Dr Jane Gibson and other Rheumatologists and Health Professionals at Whyteman's Brae Hospital, Fife. They are developing pathways for the diagnosis and subsequent treatment of those with PMR and/or GCA, in the hope of producing a more holistic approach to patient care. This will be presented at the CPG later in the year.

Finally, to fulfil our aim of supporting research, many members took part in focus groups and acted as volunteer patients and patient research partners throughout the year, working with researchers both in Scotland and further afield and we were again able to make a financial contribution to research, giving a small grant to Dr Sarah Mackie of Leeds for work relating to PMR/GCA.

Lorna Neill

Chair, PMR-GCA Scotland

www.pmrandgca.org.uk

PMR&GCAuk North East Support

Charity Reg No: 1138409

We wish to thank PMRGCAUK for the chance to update you in a small way on our activities during April 2016/2017, which has been a busy year. Further information can be found on our website: www-pmr-gca-northeast.org.uk, particularly in the newsletters 'You are Not Alone'.

We set out on this journey on 14th March 2008 and we registered as a charity in 2009. We held our first meetings in 2009 and in May 2010 we held an official launch at the Centre of Life in Newcastle with DVD called 'You are Not Alone'. Over 1,500 DVD's have been distributed not only in this country but around the world.

This year we updated our new members information packs and they now include DVD, Booklet 'Living with PMR & GCA', the steroid treatment recording book, past newsletters and other items of interest. Members also receive at least two newsletter per year. These are printed copies as we have found that existing members keep the copies for reference purposes.

Our membership fees have remained at £12 which can be paid by direct debit, monthly, quarterly or yearly. We managed to hold membership at £5 per year but sadly had to increase it to £12 a few years ago. We are lucky to have such wonderful people who consistently raise money and make donations.

This year we have also been able, once again, to help instigate new research. Last time it was to enable a young medical researcher to study "micro-vessels" a project in Barcelona. That project is still ongoing with interesting progression.

This time it is 'Your Ears' – the full story is available on our website in the winter 2016 and summer 2017 newsletters. Just in case someone has missed the publicity, we thought that we would keep this opportunity to ensure that no-one was missed out. The Research & Development section of Queen Elizabeth Hospital Gateshead NHS Foundation Trust is to do qualitative research following the result of the basic survey which we did last year on 'Your Ears'. In late May, we met with Dr Kelly and Susan Pugmire. They advised us that the NHS would now undertake qualitative research. We had donated £1,000 start-up costs. All future costs will now be paid by the NHS. They need at the very least 300 people with GCA, GCA&PMR and PMR. It would be extremely useful if we could get more patients to participate.

To take part you need to contact the Queen Elizabeth Hospital Research and Development in one of the following ways: email susan.pugmire@ghnt.nhs.uk, using the subject heading 'Research: GCA&PMR' or by post to Sister Sue Pugmire, Co-Investigator/Research Nurse, Queen Elizabeth Hospital Rheumatology Unit/Jubilee Hospital, Gateshead NE9 6SX. Make sure you include your postal address, as once your initial enquiry has been received, research documentation will be sent to you and, if via the postal service, a prepaid envelope will be supplied for you to return the completed documentation.

Our Trustees and members are looking forward to the Roadshow in the Centre of Life on 18th November 2017.

Mavis Smith

Chair, PMR&GCAuk North East Support

www.pmr-gca-northeast.org.uk