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 **NATIONAL
HELP LINE**
0300 111 5090

PMRGCAUK is a registered charity established to meet the needs of people with these debilitating conditions by raising awareness, promoting research and offering support.

Sun shines on our biggest ever Members' Day

More than 80 people from all over the country gathered in London on 9th September, to listen to guest speakers, participate in group discussions and meet others with PMR and GCA at our Members' Day and Annual General Meeting.

[For a full report, please turn to the centre pages.](#)



Photograph: © Robert Lawrie



SAVE THE DATE

PMRGCAuk Week
18th to 24th June 2018

Members' Day & AGM
Saturday 8th September 2018

London Support Group report

Many doctors are still failing to diagnose and treat PMR and GCA properly, causing unnecessary suffering to patients. That was the view expressed by London group members during their summer meeting, when they conducted a survey of attendees' experiences to help inform debate about improvements needed.

While accepting there are good doctors, a considerable percentage of members said doctors had failed to diagnose their conditions swiftly. Lack of knowledge and awareness was blamed and there was understanding that the conditions can be difficult to diagnose. But some members complained that insufficient blood tests had been carried out.

When it came to treatment, the most common problem identified was

lack of really good advice about how to reduce prednisolone doses. People were sometimes advised to reduce too quickly and, as a result, some ended up never being able to come off steroids. The need for detailed and precise advice was pressing, not just on reduction, but on subjects as diverse as weight gain, whether flu vaccination is advisable and the possible effects of GCA on the heart. Whether or not someone received a bone density scan seemed to be a bit of a postcode lottery.

Doctors need to be trained in a holistic approach to treating someone with these conditions and to realise how frightening and debilitating they can be.

Often people felt they got better information from coming to PMRGCAuk meetings than from

going to their doctors. And the group identified that the charity could usefully extend its activities to providing information suitable for family, friends and employers.

There was excitement too that new drugs are undergoing tests and hopes that future treatments would be better. And members shared their experiences with self-help. A wide range of activities had made people feel better; cycling, swimming, Nordic walking, tai chi, talking therapies, massage and 'laughter and support' were all cited.

This might have seemed like a negative session but members agreed that it is only by patients publicising the shortcomings of our experiences in the health service that real change and improvement will come.



Photograph: © Robert Lawrie



Could you be the next Chair of Trustees?

Penny Denby will be stepping down in summer 2018 after three years as Chair of Trustees. We are looking to appoint a new Chair before she finishes her term, so that there can be a substantial handover period. PMRGCAuk is an ambitious charity that achieves a great deal with very limited resources. Our membership and profile are growing and this is an exciting time to be getting involved, as the new Chair will play a leading role in the charity's development. To find out more, including how to apply, visit: www.pmrzca.co.uk/vacancies

The competition to find a Christmas card design for 2018 starts here!

If you are creative why not submit an entry?

All designs are welcome – from digital to classic artistry – and the competition is open to members of PMRGCAuk and their families.

As a first prize winner of the competition, your design will be part of our 2018 Christmas card range, on sale across the country to our members and supporters.

Money raised from the sale of our Christmas cards helps us to support the 55,000 people diagnosed each

year in the UK with polymyalgia rheumatica and the 11,000 diagnosed with giant cell arteritis.

All entries must be received by the end of the day on Wednesday 31st January 2018. To enter the competition, please submit your design with an entry form by the deadline. Entry forms and terms and conditions are available from www.pmrzca.co.uk/content/cardcompetition or 0300 999 5090.



ACROSS THE COUNTRY



MEMBERS OF THE CAMBORNE MEET UP

CAMBORNE MEET UP

Monday 9th October was a red-letter day for PMR/GCA sufferers in Cornwall, as our first meet up took place in Camborne. Nine ladies attended, three of whom also had GCA. They each told their story, with comparisons of their symptoms and treatment. The atmosphere was very relaxed and up-beat. We were also expecting three gentlemen, but they were unfortunately not able to attend. It was agreed that meetings should take place once a month initially. The meeting was enjoyed by all and I have received a couple of emails of appreciation. To join the group, please contact Margaret on camborne@pmrgca.org.uk

ILKLEY MEET UP

We are a new group, the two facilitators having met at the Rheuma Research Roadshow in Leeds. We have met in Ilkley three times so far. Five people met at first, but our numbers are growing, with eight at the September meeting and interest from about 20 people. We are getting to know each other and sharing our PMR and GCA journeys, as well as a few other unrelated stories! We are

also selling Christmas cards to raise funds for the charity.

At the September meeting, everyone wrote down their expectations of the group, the main ones being support and sharing experiences. When asked how often the meetings should take place, the answers ranged from monthly to three times a year. Our next meeting will be in December – please bring a hat, as it can be cold

on Ilkla' Moor without one! Anyone interested in joining us can contact us at ilkley@pmrgca.org.uk – both facilitators are called Sue, just to make it easy!

PMR-GCA SUPPORT EAST ANGLIA

It has been an interesting year, with a demonstration of mobility aids before the AGM in April 2017 proving popular and resulting in some members visiting the AGA showrooms to purchase various products. In July the speaker was a Diabetes UK volunteer, who stressed the importance of eating a sensible fresh food diet with moderate portions to avoid some of

the problems with diabetes.

At the most recent meeting in October, Professor Bhaskar Dasgupta gave a very informative talk to an audience of over 50, despite nearby Ipswich being gridlocked due to the closure of the Orwell Bridge. There were worried faces on all of the committee until Prof Dasgupta arrived in good time; his Sat-Nav had given him a tour of the Suffolk countryside on B roads. Points covered in his talk included the fast track pathway, use of imaging in diagnosis, the need for education in symptoms of GCA and the trials of a new drug to treat GCA.

This was the last meeting for Chairman/Organiser Maryan Fidler before she moves out of the area and she pleaded with those attending to consider becoming the next Support Group Organiser. The current committee are willing to continue if a new leader can be found. The group, one of the first in the country, was set up by Jennifer Nott in 2004. The value of the group was endorsed by Prof Dasgupta who also encouraged someone to come forward. If anyone is willing to consider filling this role, please contact kathryn@pmrgca.org.uk for more information and our huge thanks to Maryan for all her hard work.



PROF. DASGUPTA ADDRESSES THE EAST ANGLIA GROUP



Dr Sara Muller is a Research Fellow at Keele University, where she leads the PMR Cohort study.

Research Round-up

There have been many new studies published in the last few months, most of them on PMR.

POLYMYALGIA RHEUMATICA

Medical students at Keele University have published two studies looking at what happens to people with PMR. Arani Vivekanantham showed that around 15% of people with PMR report symptoms of depression¹. This is more likely in women, those who are younger when diagnosed and those who also have acid reflux. In the second study, Alex Cawley showed that having major problems with daily activities is relatively rare in people with PMR, but if they experience very severe pain or stiffness, or where it affects a large part of their body, they can have a lot of problems day-to-day².

Researchers from Minnesota, USA have shown that people with PMR do not use any more strong pain killers called opioids than people without PMR; this is important for us to know³. In a separate study, they showed that people with PMR are more likely to relapse in the first two months after diagnosis, and that despite having treatment for an average of almost 6 years – much longer than “the textbook” says – most PMR patients did not experience any more steroid-related problems (e.g. fractures, diabetes) than people without PMR⁴.

In other work, Sarah Mackie and Helen Twohig have been looking at what patients think are important outcomes in PMR. Helen has shown that the questionnaire she has been

developing, with patient input, is meaningful and acceptable to patients⁵. She will now evaluate the scientific aspects of the questionnaire. Meanwhile, Sarah has published her work with the OMERACT group (they look at measuring outcomes in rheumatic conditions)⁶. They have defined the following concepts as being key in PMR: laboratory markers of inflammation (e.g. ESR), pain, stiffness and physical function. They also identified psychological impact, weakness, physical activity, sleep and health-related quality of life as aspects for future research.

GIANT CELL ARTERITIS

There has been a systematic review of all the literature on delay in diagnosis of GCA, showing that there is an average delay of around nine weeks from symptom onset to diagnosis⁷. The authors highlight the need for improvement, but further work is required to establish whether delay causes any differences in people's outcomes.

There have also been two clinical trials. The first showed that a drug called tocilizumab could be useful in keeping patients symptom-free whilst giving them fewer steroids⁸. The researchers cautioned though that they need to follow up for longer to see that people stay symptom-free and do not develop side-effects. The second trial compared ‘usual’ prednisolone to a version that releases into the body more slowly⁹. The researchers found that outcomes for patients were similar with each treatment.

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* Epubs ahead of print



What do we know about the impact of giant cell arteritis on everyday life?

Research about giant cell arteritis has generally focused on medical aspects of the condition, including symptoms, blood tests and medication. A new study aims to discover and publicise the ways in which giant cell arteritis impacts on everyday activities, experiences and routines.

Researchers from Keele University asked for volunteers to take part in a study about giant cell arteritis. Twenty-five volunteers (9 men and 16 women, aged 65-92) took part in telephone discussions with a researcher. Some volunteers had been diagnosed with giant cell arteritis as recently as two months before the discussion, and others had been diagnosed as long as six years beforehand.

The discussions revealed that giant cell arteritis had impacted on some people's lives for only a short time, or not at all:

"As far as living with it goes, to be quite honest I haven't found any real change"

(David, age 71, 2 years 5 months since diagnosis)*

In contrast, other people reported that their everyday lives had been affected for many years after their diagnosis. These longer-term effects were described as 'restricting' and 'life changing'. It was often difficult for people to carry on with everyday life as normal:

"I struggle to cook. I struggle to do housework. I struggle with everyday living"

(Dorothy, age 78, 2 years 11 months since diagnosis)*

Areas of life that people said were affected by giant cell arteritis included:

- Work and volunteering
- Relationships
- Hobbies, social and leisure activities
- Household tasks, daily routines and personal care
- Financial circumstances
- Driving

Importantly, the study showed that it was both the symptoms of giant cell arteritis and the side effects of its treatment that affected how easy it was for people to continue living their lives as normal. These symptoms and side effects included exhaustion, pain, sight loss and other visual symptoms, changes in mood, changes in people's physical appearance, and changes in sleep.

Some people felt less confident because of changes to their physical

appearance or because they had a visual impairment. People also worried about the possibility of losing vision at some point in the future, and did not know how likely this might be.

By researching and publicising the different ways that people experience giant cell arteritis and its treatment, the study team hope that it will be easier for doctors and patients to discuss ways to reduce unwanted impacts on everyday life.

The full academic report of this study can be read and downloaded for free: <http://bmjopen.bmj.com/content/bmjopen/7/8/e017073.full.pdf>

* All names have been changed to maintain anonymity.

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"An uplifting day."



"The atmosphere/feeling was positive and friendly."

MEMBERS' DAY

On Saturday 9th September, more than 80 people gathered in London for the seventh PMRGCAuk Members' Day and Annual General Meeting – our biggest turnout ever.

In the AGM section of the day, members voted to accept the Annual Report and Accounts, after Chair of Trustees Penny Denby gave her overview of the year's achievements.

With the formalities completed, we were delighted to be joined by two speakers, Dr Jo Robson, consultant senior lecturer in rheumatology at the University of the West of England, Bristol and Anne O'Brien, senior lecturer in physiotherapy and director of learning and teaching in the School of Health and Rehabilitation at Keele University.

Jo and Anne both gave fascinating talks that were very well received. Jo spoke about her research into patient perspectives of GCA and then held a Q&A with the audience. After lunch, Anne spoke about her research into physiotherapy assessment and management of PMR, and then got us moving with some gentle seated exercises.

The small group discussions were lively and interesting, with lots of extremely valuable contributions. However, with the room filled almost to capacity, the noise level unfortunately presented a big problem for this session. We will find a way of addressing this for next year's event.

One of the most valuable aspects of Members' Day was the opportunity for people to meet others with PMR/GCA and share experiences. There was time set aside at the beginning and end of the day – as well as over lunch – for mingling and chatting. Thanks to all those who attended and made the event a great success, especially to the many volunteers who helped things run smoothly. Thanks also to those

who left feedback; your comments will enable us to organise an even better Members' Day next year.

Change to Membership Fees

During the AGM, Chair Penny Denby explained that the trustees are planning to change the membership fee structure for the charity in early 2018.

Membership fees will change, from the current £10 for retired/unwaged people and £25 for waged people, to a single subscription rate of £15 a year.

Combining the rates will make it simpler for everyone and we hope it will ensure that people who are low waged (perhaps working part-time) are not paying more than they can really afford. The increase from £10 to £15 also means that the subscription will go further towards the cost of membership services, such as sending out NewsWire.

The majority of our members already fall into the retired/unwaged category, and many people – waged and unwaged – add a donation to their annual membership fee. We are very grateful for these donations which are



"I was inspired by Janice [Maddock, Trustee] to become an ambassador. Now I am feeling more confident and better in myself I realise I could do this with her support."

an absolutely crucial source of income. We do hope that people will continue to donate at whatever level they can afford. In this way our members enable us to help others with PMR and GCA, especially those who are newly diagnosed.

After outlining the plan, Penny invited comments from members and those who spoke supported the change, as did an indicative show of hands.

For minutes of the AGM and other information about the 2017 Members' Day please visit: www.pmrzca.co.uk/content/agm2017

"Thank you for organising the day. It was well worth coming."

GROUP DISCUSSIONS

Here are a taste of the responses from the small group discussions. You can read a fuller list at www.pmrzca.co.uk/content/agm2017

What functional or day to day activities have been the most difficult for you to do since having PMR/GCA?

Among the activities mentioned by members were getting out of bed or a chair, putting on underwear and getting dressed, carrying shopping, doing housework or gardening, enjoying time with grandchildren, climbing stairs, concentrating and thinking of the right words, playing tennis, blow drying hair and attending social events.

Have any movements or exercises helped you to cope? What advice or tips can you share?

There were many useful ideas including pilates, swimming, Nordic walking, golf, osteopathy, dog walking, tai chi and cycling. Sound advice included 'know your limitations', 'pace yourself' and 'be kind to yourself'.

What can PMRGAuk do to better support you with taking and tapering steroids? What information, resources and support would make a difference?

Suggestions included advertising HealthUnlocked more widely, providing more printed materials for those who don't use the internet, educating GPs and other medical professionals, helping to find good speakers for group meetings and conducting a study into how people successfully taper their steroids.

What advice or tips can you share?

Members advised building confidence so you can have educated conversations with doctors, using the tapering app (featured on p10), reducing your dose on days when you are less busy and not rushing to reduce but listening to your body.

Write Me Funny...

A new book on PMR and GCA

Following his popular, humorous blog on the PMRGCAuk HealthUnlocked forum under the guise of markbenjamin57, Mark's witty ramblings are now available as an illustrated paperback book.

'Write Me Funny...' is intended as an antidote to the important but often serious publications about PMR/GCA. With his gentle but mischievous humour, Mark cheekily refers to his friends and followers in the PMRGCAuk community as 'You Lot' and 'Polymalingerers', entertaining readers with various, often fictional accounts of experiences, characters and scenarios on his PMR journey. Cartoons by Anthony Allen bring the content alive, making the book a 'must read' for PMR and GCA survivors who want something light-hearted and different.

Mark says: "At first, my silly ramblings were really just an effort to see the lighter side of PMR during the long days and weeks of feeling fed-up and exhausted with this horrible illness. But, to my delight, lots of other forum members soon joined-in with equally playful banter: and it made me realise that others with chronic illnesses like PMR and GCA often appreciate some fun and laughter to help us through the tough bits too. On a health

journey that none of us chose to make, it's a privilege to share some smiles with fellow PMR and GCA survivors - and for PMRGCAuk to benefit financially at the same time."

Some quotes from Mark's followers on the PMRGCAuk HealthUnlocked forum:

"Thank you, Mark. You are a ray of sunshine on a very gloomy day."

"Screamingly funny, and so true.."

"Thanks Mark for a good laugh to start the day, was feeling a bit down but much better now. From another Polymalingerer."

"Made me hoot out-loud in my open plan office - hell! Thank you!"

"Brilliant - laughed my socks off! "

"I woke up this morning and read this, Mark. Thank you - a smile is a great way to start the day!!!"

'Write Me Funny...' is available initially as a paperback book exclusively via PMRGCAuk, with 25% of the net sale proceeds donated directly to the charity in appreciation of its support. To find out more and order Mark's book, go to www.pmrzca.co.uk/content/book

Miracles take a wee while longer - but they can happen!

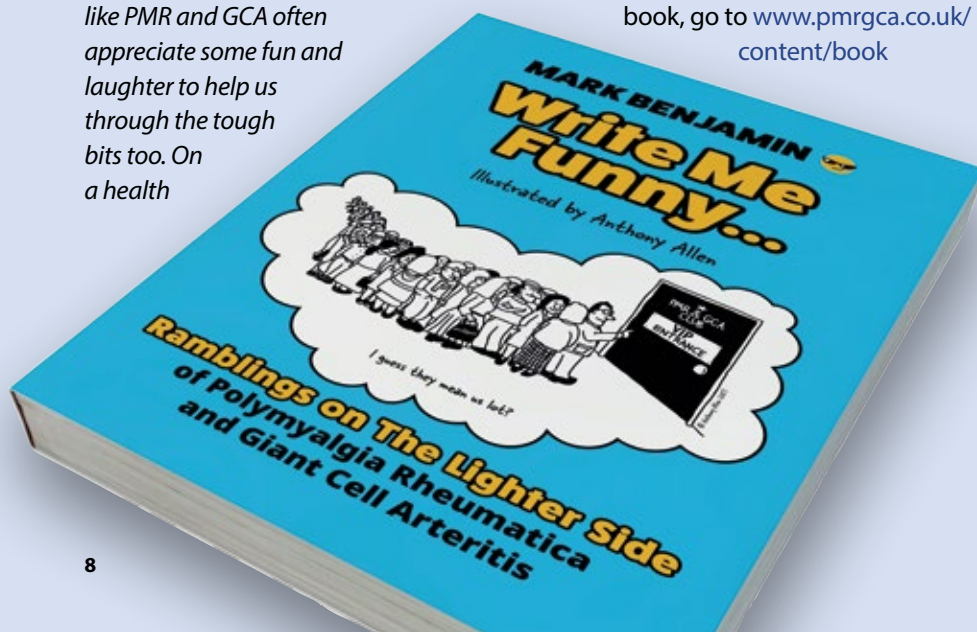
PMR-GCA Scotland member **George Allan** tells his story

I think I have been one of the very lucky ones. This is a brief description of what seems to be an unusually speedy recovery from PMR. After 4 or 5 months of worsening symptoms, I was waiting to attend an appointment with the neurologist when, on 4th April 2016, I was taken by ambulance to the neurological ward at Ninewells Hospital in Dundee in a state of almost total immobility and with considerable pain in my neck, arms, shoulders and legs.

After two days of tests, MRI, CT, EMG and loads of other prodding and manipulations, I was diagnosed with PMR and given an initial dose of prednisolone. The following morning I was virtually pain free. My wife could not believe I had got out of bed by myself when we FaceTimed at 8am!

A further two days later, I was discharged from hospital with a pharmacy of medicines, in particular a starting dose of 15mg prednisolone per day. I followed the NHS Tayside tapering regime and now, over a year later, I am down to the last 8 weeks of 1mg per day.

Over the course of treatment, I had my bloods checked every 4, then every 8 weeks as per the schedule. On each occasion the bloods were okay and I had no pain, so I was able to reduce to the next level. Maybe this is a case of PMR 'burning itself out'. I am so lucky as I know many of my fellow group members have endured the condition for many years. Fingers crossed that I have no flare-ups!





NEW TRUSTEE

We are delighted to welcome Marion Read as a trustee. Marion attends the Edinburgh group and increases the geographical spread of the trustees.

FIFE STUDY DAY

In June four members, two with PMR and two with GCA, presented themselves at St Andrews Community Hospital, where we had volunteered to take part in a Training Day and Study Morning. A large turnout included rheumatologists and rheumatology nurses, along with staff from occupational therapy, physiotherapy and pharmacy. The meeting had been organised by Dr Jane Gibson, consultant rheumatologist, Fife Rheumatic Diseases Unit, Whyteman's Brae Hospital, Kirkcaldy.

Dr Helen Harris spoke first on PMR, updating us all on current knowledge about the illness and its treatment. Then Dr Gibson did the same for GCA, emphasising the importance of the Fife Quick Access pathway. After that, members of the charity spoke individually with small groups of staff, telling their stories and answering questions to give the patient's viewpoint. These groups rotated until everyone had had a chance to talk with each patient.

From the discussions, Drs Gibson and Harris intend to produce treatment pathways for both PMR and GCA, including the treatment of flares. The aim is to use a holistic approach to ensure that elderly patients with pain and mobility problems, and often other co-existing illnesses, can have access to all the aspects of healthcare they need. This includes pain control to ensure physiotherapy

can take place and advice from an occupational therapist to lessen day to day frustration with household tasks and self-care.

Our members were all impressed with the desire of the staff to listen and to learn from our experiences and their obvious commitment to bring all their different professional expertise to provide the best possible care. Any group who are encouraged to "think patient, not steroids" is well on the way to getting it right!

ANGUS HEALTH FAIR

September saw Christine and Margaret from the Dundee Support Group join me to set up a stall, along with others from every aspect of healthcare, in the Reid Hall, Forfar. We gave out leaflets and copies of NewsWire to members of the public, healthcare professionals and stallholders from other charities. As always it was a great opportunity to network, talk to the public and to fly the flag (or at least the PMR-GCA Scotland banner).

HIGHLAND SUPPORT GROUP

Thanks to all the hard work put in by David Carrott we had a well-attended inaugural meeting of the new Highland Group in the Spectrum Centre Inverness on 27th September. Subsequent meetings will be on the first Fridays of November and December this year, then changing to Wednesdays during 2018. Members can meet, if they wish, in the Hidden Gem cafe for lunch around 12.30 with the meetings being held in the Concourse Room from 1.30 till 2.30pm. Please see www.pmrangca.org.uk for further details.

FORTHCOMING EVENTS

Finally, at the time of writing, we are looking forward to the Rheuma Research Roadshow event, to be hosted by Dr Gibson at the Victoria Hospital, Kirkcaldy on the 1st November. Thank you Kate Gilbert and PMRGCAuk. This is closely followed by a chance to have the importance of Fast Track diagnosis for GCA brought to the notice of the Scottish Parliament at one of its Cross Party Groups on the 8th November. Guess who is speaking on our behalf? None other than Dr Jane Gibson! Our grateful thanks, Jane, for all you have done on behalf of PMR and GCA this year.

Lorna Neill
Chair of PMR-GCA Scotland



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Launch of the Steroid Taper Web Application

Having become a regular "visitor" to the PMRGCAuk forum on the HealthUnlocked network since my diagnosis of PMR early in 2015, I am particularly interested in other people's experiences of tapering steroids.

Following a flare in 2016, when I had to go back up from 3mg to 10mg, I began researching ways of preventing another flare whilst continuing to reduce my daily dose and looked to the forum for advice. Many users reported a successful taper using one of the "Dead Slow Nearly Stop" methods that are discussed frequently so my plan, once I had reached 5mg, was to try one of these methods.

Around this time I was looking for some inspiration and ideas for an IT project that I needed to do to complete my Bachelor of Science Honours Degree in Computing & IT. Contributors to the HealthUnlocked forum had come up with various ways of keeping track of a taper schedule, from recording their planned dose in a diary or on a calendar to plotting their schedule on graph paper. Other contributors who were more interested in technology used an electronic diary or created a spreadsheet. Unfortunately, many of us create schedules that, due to the nature of both PMR and GCA, don't go according to plan and this gave me the idea to create the steroid taper web application.

Contributors to the forum have been helping me create an application that can be accessed through any device that has a web browser and an internet connection, so this includes

smart TVs, mobile phones, tablets, laptops and PCs.

Basically, the steroid taper web application is a resource that stores copies of steroid taper plans which can be viewed online or downloaded. To make it really easy for users to be able to plan a taper, the application stores the patterns of these taper plans. Users can then select a taper and the application will create a personalised schedule which is displayed on a monthly calendar with the dose that should be taken displayed beneath each day. Schedules can be reset and

edited should this become necessary.

The application can be accessed via www.pmrzca.co.uk/content/steroidapp and I would like to take this opportunity to thank everyone who has helped and supported me in its development.

Sandra Isitt

The choice of any taper plan should be a shared decision between doctor and patient taking into account individual factors. Your GP and rheumatologist should always be aware of the plan you are following.



Join our PMRGCAuk community and make your experience count

PMRGCAuk
HealthUnlocked

Get help to manage your health and lifestyle from others with polymyalgia rheumatica and giant cell arteritis and from the charity, PMRGCAuk.

It's free, easy to use and it's just waiting for you!

The online community gives you:

- Answers to your health questions from other patients
- Support from other PMR and GCA sufferers
- Ideas for treatment and lifestyle choices that could help
- Health issues and debates relevant to you



Take control of your health and join today

pmrgcauk.healthunlocked.com

Money, money, money Could you help us fundraise?

Charities often raise funds by approaching known supporters and asking them to make donations.

Recently, one of our members decided to promote the giving of donations by people not previously connected to PMRGCAuk. This is how they did it. The member and their spouse held a large party for family and friends to celebrate the spouse's 70th birthday. All the invitees were asked to bring no presents BUT the invitation included:

*"No presents please BUT DONATIONS
IF YOU WISH: to PMRGCAuk via
uk.virginmoneygiving.com/charities/PMRGCAuk or to another charity of your choice."*

Most of the guests knew that the member has PMR and the result was that many sent donations to PMRGCAuk - in total more than £1,500. What an amazing result.

Since 2015, Gloria has donated £220 to PMRGCAuk, which she has raised in various ways - for example, by helping others in her Retirement

Village with their IT problems and sewing alterations, and by nominating the charity to benefit from a sale of new and nearly new donated items in the Village. Thank you so much for your innovative fundraising, Gloria.

In June, Patricia and the Chichester Meet Up held a coffee morning and plant sale in aid of PMRGCAuk Week. Despite inclement weather the group had an enjoyable morning, chatting, drinking coffee and choosing plants in Pagham. They donated a marvellous total of £100 - a previous mini-plant sale having raised £13.50. Thank you Patricia and all for supporting our fundraising week.

If you have a fundraising idea to share, or are willing to help but would like some inspiration, please do get in touch with fundraising@pmrgca.org.uk - we would love to hear from you.



PMRGCA: A SURVIVAL GUIDE

Since its publication this book has quickly become a bestseller. Kate Gilbert, PhD. distilled what she learned from having PMR (and recovering!), and from years of working alongside other sufferers, rheumatologists and researchers, as a trustee of PMRGCAuk. Kate says "I have tried to write the book that I would have liked to read when I had PMR, not only when I was first diagnosed, but also a few months in, when I realised that it wasn't going to be as straightforward as they had led me to believe."

It is now available for Kindle and in paperback from Amazon <http://bit.ly/pmrbook2ed> Price for the paperback is £10.03 plus p&p. If you are unable to order the book from Amazon, write to polywotsit@gmail.com to order via PMRGCAuk.

Member Survey Results

We were delighted that 209 people completed our 2017 Members' Survey and would like to thank you all for your help. Here's a sample of the results:

- 57% of respondents have PMR, 14% have GCA and 14% have both.
- Only 23% had heard of PMR or GCA before their diagnosis.
- 97% of those who expressed an opinion agreed that they find it helpful to meet other people with the same condition at support groups.
- 98% of those that expressed an opinion agreed that they received useful information during a call to our telephone helpline and 100% agreed the volunteer they spoke to was a good listener.
- 85% of respondents chose being on and tapering off steroids as one of their top five priorities for support.

There were also lots of interesting and constructive comments which will help us to improve our services. Full results are now available on our website www.pmrsgca.co.uk/content/survey2017

The winner of a signed copy of the second edition of Kate Gilbert's book *Polymyalgia Rheumatica & Giant Cell Arteritis: a survival guide*, was Jean Lloyd.

WITH GIVE AS YOU LIVE, YOU CAN RAISE MONEY FOR PMRGCAUK FOR FREE

Give As You Live is a simple way to raise funds by shopping online. Set up a free account, browse participating retailers from the Give As You Live website each time you shop online (this connects your shopping to your account) and by using the links provided, visit the retailer you want, and shop online as normal. Give As You Live turn the retailer commission they receive into a donation to our charity and PMRGCAuk supporters have so far raised £120 for us. If you need help to set up and use Give As You Live, please contact catrina@pmrgca.org.uk or visit www.pmrsgca.co.uk/content/shop-n-support to find out more.



SUPPORT GROUP AND MEET UP CONTACTS

Our network of groups around the country is growing! Scotland and the North East are independent organisations. If you don't have a group near you and would like to help us start one, please contact groups@pmrgca.org.uk or 0300 999 5090.

NORTHERN IRELAND

LISBURN MEET UP

Contact: Caroline Stewart
pmrgca.ireland@gmail.com

SCOTLAND

PMR-GCA SCOTLAND

Contact: Lorna Neill (Chair)
www.pmrangca.org.uk
info.scotland@pmrangca.org.uk
Tel: 0300 777 5090

WALES

CARDIFF MEET UP

Contact: Sue
cardiff@pmrgca.org.uk

NORTH EAST ENGLAND

PMR & GCA UK NORTH EAST SUPPORT GROUP

Contact: Mavis Smith
www.pmr-gca-northeast.org.uk
Tel: 0191 4111138

NORTH WEST ENGLAND

ILKLEY MEET UP

Contact: Sue
ilkley@pmrgca.org.uk

KENDAL, CUMBRIA MEET UP

Contact: Win Sayers
groups@pmrgca.org.uk
Tel: 01539 535859

MIDLANDS ENGLAND

COVENTRY MEET UP

Contact: Anne Hollingsworth
pmrgca.coventry@gmail.com

SHROPSHIRE SUPPORT GROUP

Contact: David Davies
shropshire@pmrgcauk.com

EASTERN ENGLAND

BEDFORD MEET UP

Contact: Lyn / Karen
bedfordshire@pmrgca.org.uk

CAMBRIDGE SUPPORT GROUP

Contact: Claire
groups@pmrgca.org.uk

EAST ANGLIA SUPPORT GROUP

Contact: Claire
groups@pmrgca.org.uk
Tel: 01787 379400

PETERBOROUGH SUPPORT GROUP

Contact: Clare Marshall
peterboro@pmrgcauk.com

SOUTHEND/ESSEX SUPPORT GROUP

Contact: Pat Fedi
southend@pmrgca.org.uk
Tel: 07722 827 947

SOUTH WEST ENGLAND

BATH MEET UP

Contact: Pat Martin
pmrgca.bath@gmail.com

BRISTOL GROUP

Contact: Wendy Morrison
bristol@pmrgca.org.uk
pmrgca.southwest@yahoo.co.uk

CAMBORNE MEET UP

Contact: Margaret
camborne@pmrgca.org.uk

CHRISTCHURCH MEET UP

Contact: Deidre Harding
pmrgca.christchurch@gmail.com

PLYMOUTH AND CORNWALL SUPPORT GROUP

Contact: Keith Bulley
plymouth@pmrgca.org.uk

SALISBURY MEET UP

Contact: Patrick O'Donnell
pmrgca.salisbury@gmail.com

SOUTH WEST (TAUNTON) SUPPORT GROUP

Contact: Wendy Morrison
pmrgca.southwest@yahoo.co.uk

TORBAY MEET UP

Contact: Trish
pmrgca.torbay@gmail.com

GREATER LONDON, ENGLAND

GREATER LONDON SUPPORT GROUP

Contact: Anne
londonpmrgcauk@gmail.com

BARNET SUPPORT GROUP

Contact: Derek
barnet@pmrgca.org.uk

HIGH WYCOMBE MEET UP

Contact: Alison/Sue
pmrgca.highwycombe@gmail.com

SOUTH AND SOUTH EAST ENGLAND

BRIGHTON MEET UP

Contact: Catherine Spencer
brighton@pmrgca.org.uk

CHICHESTER MEET UP

Contact: Patricia Dawson
chichester@pmrgca.org.uk

HASTINGS MEET UP

Contact: Brenda Wilson
pmrgca.hastings@gmail.com

MAIDSTONE MEET UP

Contact: Margaret Hicks
pmrgca.maidstone@gmail.com

ORPINGTON MEET UP

Contact: Penny
pmrgca.orpington@gmail.com

OXTED MEET UP

Contact: Debbie Pitt
pmrgca.oxted@gmail.com

PORT SOLENT MEET UP

Contact: Barbara Winspear
pmrgca.portsolent@gmail.com

SEVENOAKS MEET UP

Contact: Penny
pmrgca.seveonaks@gmail.com

SURREY SUPPORT GROUP

Contact: Shirley O'Connell
surrey@pmrgcauk.com

SUSSEX/SOUTH COAST SUPPORT GROUP

Contact: Christine/Catie
pmrgcasouthcoast@btinternet.com

WORTHING SUPPORT GROUP

Contact: Christine/Catie
worthing@pmrgca.org.uk

If no telephone number is listed for your group, please call the office on 0300 999 5090.