



## Fast action wins PMRGCAuk a £1,000 Movement for Good award

### INSIDE THIS ISSUE

- 02** INFORMATION AND TIPS FOR PEOPLE WITH PMR AND/OR GCA  
Including a 'record your dose' spreadsheet
- 03** RESEARCH ROUND UP  
Recent GCA research
- 04** ACROSS THE COUNTRY  
News from the groups
- 05** 3 GROUP LEADERS...  
share their experience of setting up a group
- 06** MEMBERS' DAY AND AGM 2019  
Details of this year's event
- 07** PMRGCA SCOTLAND  
News from north of the border
- 08** FUNDRAISING & AWARENESS  
PMRGCAuk Week reports, tea with 'the real' Doc Martin and things you can do to help
- 10** SHARE YOUR STORY  
'Is Nanny all right?'  
A personal experience
- 11** JOIN OUR HEALTH UNLOCKED  
ONLINE COMMUNITY  
and volunteering opportunities
- 12** SUPPORT GROUPS  
All the contacts you need

 **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.

PMRGCAuk was successful in winning a £1,000 grant as part of Ecclesiastical's Movement for Good awards, giving £1million to charities this summer. Members of the public were invited to nominate causes close to their hearts, with 500 gifts of £1,000 available for donation. Rowena Lake, a member of the Taunton Support Group spotted the opportunity on Facebook at the last moment, leaving us just 24 hours to get the votes in for PMRGCAuk before the closing date, "I let the charity

know that I had voted for them and then they quickly let others know that they could do the same. Having been diagnosed with PMR and GCA in 2016, I owe a lot to the charity for the support and help they have given me, as well as that from the Taunton Support Group. I am so pleased that the charity has benefited." With members, volunteers and staff all jumping into action, PMRGCAuk became one of the 7,000 charities nominated by 98,000 members of the public.

### PMRGCAuk Week

Events took place around the country in support of PMRGCAuk Week on 18-24 June, including sponsored runs, coffee mornings, bring & buy sales, pub quizzes and awareness raising events in GP surgeries, to mention a few. One member, Pauline Bain, who has PMR, ran 5km every day to raise awareness of PMR and GCA, "In May 2018 I was diagnosed with Polymyalgia Rheumatica after being crippled with pain for two months and I was started on steroids. My GP has been amazed at my determination and progress in battling PMR. I threw myself into running and love it so much that I try to run as much as I can, despite still suffering from PMR flare ups."



## 2019 Members' Day & AGM – 7 September

**Will you be joining us? See inside for more details**

Members' Day is all set for Saturday 7 September, with speakers **Dr Chetan Mukhtyar**, Consultant Rheumatologist at Norfolk & Norwich Hospital and **Dr Sara Muller**, Senior Research Fellow at Keele University. The event will take place at a new venue this year, Greenside Community Centre, close to Marylebone and Edgware Road stations. The popular day will be chaired by Professor Humphrey Hodgson and provide an opportunity to meet others with PMR and GCA and share experiences, "We are always delighted by the calibre of the speakers we attract to our Members' Day and this year is no exception. We are incredibly grateful for the time they give up to some and speak and to the effort our Members make in attending. It's a wonderful opportunity to get together."

# Information and Tips for people with PMR and/or GCA

Professor Bhaskar Dasgupta attended Group meetings in Cardiff and Bristol back in May and discussed top tips for those with PMR and GCA.

1. Have your eyes tested once a year when taking steroids as they can cause damage to the eyes such as cataracts and glaucoma. You should also have an annual check for blood sugar control (HbA1c), blood cholesterol (fasting lipids) and regular blood pressure checks.
2. If you have GCA and have been on high levels of Prednisolone, and then start having eye problems like double vision, this is more than likely a result of the Prednisolone and not due to GCA – particularly if the problem occurs in both eyes, as GCA usually only affects one eye.
3. Side effects of steroids are most pronounced when the dose is 10mg daily or above and the total accumulated dose is more than 5-6 grams. If this cumulative dose is exceeded you should discuss with your doctor regarding alternatives. To keep the risk of side effects low, it is very important to get the dose exactly right for your needs – not 1mg more or 1mg less. Fortunately the benefits of maintaining Prednisolone under 5mg such as 1-3mg daily generally override the risk of side effects.
4. Everyone should be encouraged to keep a record of their cumulative dose of Prednisolone and take it with them to their medical appointments – see box opposite.
5. Discuss the risks of osteoporosis with your doctor.
6. Sometimes as Prednisolone is reduced and pain returns; this is from the PMR symptoms reappearing. However, it may be pain from osteoarthritis which is no longer being masked by the steroids. In this instance it is better for non-steroid pain relief to be used.
7. Exercise is important; steroids cause myopathy (muscle damage/wasting) and fluid retention can occur which causes swelling in your lower legs and ankles. Exercise is the key to maintain muscle strength and improves circulation. Once muscle fibre is lost, it cannot be regained.
8. Long term use of Prednisolone can cause depression. It can also cause sleep disturbance that leads to poor quality non-refreshing sleep, tiredness and lack of energy.
9. CRP is the gold standard blood test for PMR and GCA because it is the same test throughout the world. (The techniques for measuring ESR and viscosity vary in different laboratories.) A persistent CRP reading above 10 is a cause for concern – but remember levels of CRP, ESR and viscosity can rise in many other conditions and aren't specific for PMR and GCA... Steroid dose should not be adjusted based on

blood test results alone, and, there is no need for checking blood tests too frequently.

10. Cut back or cut out alcohol when taking corticosteroids. A well-balanced diet with adequate dairy intake will help in reducing steroid side effects.
11. In many parts of the country, patients are already able to access their NHS records online and can then check the results of their blood tests. Please check whether this is possible with your own GP practice. You can also nominate someone you trust to access them, through GP online services. It is important for you to understand the meaning of the blood test results.



## RECORD YOUR DOSE

We have produced an Excel spreadsheet that you can use to help you record your cumulative dose of Prednisolone. Download your copy from our website: <http://www.pmr-gca.co.uk/downloads/2/> and save it to your PC, or email [info@pmr-gca.org.uk](mailto:info@pmr-gca.org.uk) to request one. We can also send you a hard copy.



Thanks to one of our volunteers Catrina Zahoor for producing the spreadsheet.



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

## RESEARCH ROUND UP

Last time, all the recent research seemed to be about PMR, but this time, it's the turn of GCA. Most studies are about improving diagnosis or the drug Tocilizumab.

Studies from France and Australia have shown that scans called PET-CTs could be useful in the diagnosis of GCA<sup>1,2</sup>. However, these studies are not likely to change the diagnostic process in practice in the near future. Other studies have tried to develop scoring systems to work out the chance that someone has GCA<sup>3,4,5</sup>. However, more work is needed to test how well these scores will work in practice. We also need to understand better the groups of people in whom they might be useful (e.g. people who had a biopsy, people with PMR).

A meta-analysis (pooling the results) of studies of steroid treatment in GCA has shown that relapses (return of symptoms) happen in around 47% of patients<sup>6</sup>. Occurrence of a relapse seemed to be more likely if a patient was treated with steroids

for a shorter period of time. However, the starting dose of steroids, the age and sex of the patient were not associated with the risk of relapse.

Further results from the GiACTA study (Newswire 21 – Spring 2017) have shown that symptom control can be achieved more quickly in people treated with Tocilizumab as well as steroids<sup>7</sup>. Perhaps unsurprisingly, these researchers were also able to show improvements in overall quality of life and fatigue levels in people receiving Tocilizumab as well as steroids<sup>8</sup>. However, it is worth noting that even with Tocilizumab treatment, around a quarter of people still experienced a flare in symptoms (compared to just over half with only steroids)<sup>7</sup>.

A separate study has shown that the risks of side effects from Tocilizumab may be higher in GCA than in rheumatoid arthritis, a condition where we know a lot more about this drug<sup>9</sup>. This is an area that may need further work.

Using data from a different trial of Tocilizumab, other researchers have tried to understand for how long treatment with this drug may be needed. They found that the 1 year of treatment given in their trial resulted in around half of patients experiencing a relapse, but they were unable to predict who would remain well<sup>10</sup>.

Finally, something that is unlikely to affect treatment in the short-term, but is none-the-less encouraging, is the development of a 'core set' for GCA by the European League Against Rheumatism (EULAR). This Europe-wide network has decided on over 50 key things related to GCA that should be recorded about each patient to improve care and also facilitate research into the condition<sup>11</sup>.

### References

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# ACROSS THE COUNTRY



Professor Dasgupta visited Bristol in May

## GROUPS: THE PMR+GCA ARMY OF SUPPORT!

One of the key strategic objectives of PMRGCAuk is to set up more Groups and Meet Ups around the country to help ensure that everyone has the opportunity for face to face support. While Groups can be more formal and include expert speakers, Meet Ups tend to be more informal in nature, where individuals might meet in a relaxed environment such as a café or restaurant to share experiences and support each other.

Interested in setting up a Group or Meet up in your area?

Contact [candy@pmrgca.org.uk](mailto:candy@pmrgca.org.uk) to find out more

### BRISTOL

Forty members attended the Bristol Speaker Meeting in May at The Holiday Inn City Centre. Terrie Stocker, Osteoporosis Nurse Specialist in the Rheumatology Department at the Bristol Royal Infirmary gave a very interesting presentation on Osteoporosis, followed by keynote speaker, Professor Bhaskar Dasgupta, Consultant Rheumatologist and President of PMRGCAuk, who talked about PMR and GCA. The event was very well received by all. Thank you to both speakers and regional co-ordinator Wendy Morrison for a wonderful event, which also raised £116 for PMRGCAuk.

### CARDIFF

Professor Dasgupta also visited the Cardiff Group in May which was well-attended, including those who had travelled quite long distances. He spoke mainly about Giant Cell Arteritis, explaining the system of fast-tracking for professionals and patients to obtain a diagnosis of GCA. While this process works well in some areas of England, there is no such thing in Wales, and many of the Group had waited months, even years, before being diagnosed. The talk also highlighted the harmful effects of long-term steroid therapy, a topic of great interest to everyone. Everyone enjoyed the talk and the Group has hopefully gained some new members from the meeting – as well as raising £120!

**“Thank you so much for the meeting last week. It was a great success and so informative. I am sure everyone gained information from both talks which were helpful and reassuring.”**



# 3

## GROUP LEADERS... share their experience of setting up a Group

### Jennifer's story

**The Harrow/Pinner Meet up Group run by Jennifer McIlvenny was set up in autumn 2018, with support from Janice Maddock, a Trustee and Catrina Zahoor, a volunteer.**

"I have suffered from Polymyalgia since 1998. I had the stiffness and aches associated with PMR but as a retired nurse, I was used to these aches and pains. The GP diagnosed grief, as my husband had died just 5 months earlier, but I knew the difference between grief and malaise. Two and a half years later my new GP took blood tests; he asked me if I could comb my hair and I replied as I raised my arms "Yes, but I don't like to and don't tell me I have Polymyalgia".

Last year I had a bad flare and felt quite alone and depressed, especially as so many friends would say "But you look so well". I found PMRGCAuk via Arthritis UK and during a long chat with a volunteer my spirits were restored and I realised I was not alone. I joined PMRGCAuk and attended the AGM/Members' Day. So many people feeling like me from all over the country!

Realising that there were other people in the Harrow/Pinner region also suffering, I decided to start a Meet Up Group. At the first two meetings only one person, the same lady, attended, but by the third meeting it had grown to 11! Those attending, most of whom were recently diagnosed, were so pleased to voice their concerns, get ideas and support from others that the 2 hours sped by. The support available from Kate Gilbert's book, the charity - and in particular the Telephone Helpline - were brought to the group's attention. Their relief in discovering that they were not alone with this strange illness was so very evident.

We plan to invite speakers to future meetings, and I've already sounded out my Rheumatologist, Pharmacist and Physiotherapist!"

Contact: [harrow@pmrgca.org.uk](mailto:harrow@pmrgca.org.uk)

### Thomas's story

**Thomas Withers is Group Organiser for the Whitstable group, and has been supported by Penny Denby, Trustee and Candy Horsbrugh, Deputy Director.**

"In October 2018 I developed a "frozen shoulder". I had a couple of jabs, the relief lasted two weeks and I was then put on steroids. I then had a serious chest infection and for 3 months I was in a lot of pain and discomfort with PMR. I thought there must be a Support Group out there, (there is a support group for any illness or disability) but when I looked up the support group for PMR, I found they were in Maidstone or Orpington, some 27 miles away. They have their meeting at 11am, at that time I was lucky to be able to get out of bed by 10am!

I am a member of the Whitstable Medical Practice Patient Participation Group (PPG) where the group meet with the practice manager and others senior members (GP's) to encourage patients to put forward views and ideas on local healthcare services. I asked if they could advise me of the number of patients with PMR or GCA and they told me there were 375! This spurred me on to setting up a Whitstable Group. The Whitstable Medical Practice has been very supportive, and messaged these patients to contact me. So far, we know of 25 people who want to join our Support Group.

Our first meeting took place at the end of June at the WI Building in Seasalter, Whitstable and I am really looking forward to future meetings."

Contact: [whitstable@pmrgca.org.uk](mailto:whitstable@pmrgca.org.uk)

### John's story

**John Robson took over the running of the group in the North East in March 2019, with the support for Wendy Morrison, a Trustee.**

"We re-established the North East Group under the auspices of the national charity on 28th March with a meeting in Durham, with Wendy Morrison (PMRGCAuk Trustee) introducing the charity to 20 people who attended from all over the North East and even Cumbria. We had a discussion around health issues and then I gave a presentation that introduced my 'A-Z of Life in Remission with Polymyalgia Rheumatica'.

We hosted our 2nd meeting in Durham in July and welcomed Mr. Saravanan Vadivula (Gateshead NHS Trust) and Dr. Sarah Mackie (Leeds NHS Trust). Both medical professionals have been heavily involved in PMR/GCA research and patient support for 10 years and they let members know about future plans for GP's to receive training in the North East following the donation from the original PMRGCAuk North East Support Group.

Over the next 12 months we hope to start establishing smaller meeting groups in and around the North East with the Durham meeting being the main hub."

Contact: [northeast@pmrgca.org.uk](mailto:northeast@pmrgca.org.uk)



# Members' Day & AGM 2019

Greenside Community Centre, 24 Lilestone Street, London NW8  
**Saturday 7 September 2019**

You are invited to attend Members' Day and AGM on Saturday 7 September, our annual event for Members and friends of PMRGCAuk

## Programme (provisional)

- 11.00 Registration and refreshments
- 11.30 AGM
- 12.30 First speaker
- 13.15 Buffet lunch
- 14.15 Second speaker
- 14.45 Third speaker
- 15.30 Closing remarks
- 15.35 Refreshments and networking
- 16.00 Close

## Guest speakers

**Dr Chetan Mukhtyar:** Consultant Rheumatologist, Norfolk & Norwich University Hospital and Honorary Senior Lecturer at University of East Anglia will describe the patient journey of someone with suspected GCA in Norwich including the triage, diagnostic and therapeutic interventions, follow-up arrangements and managing relapses and answer your questions on GCA and PMR.

**Dr Sara Muller:** Senior Research Fellow at Keele University and Trustee of PMRGCAuk will talk about the latest research into PMR and GCA.

**Third speaker:** announcements coming soon!

## How to book

Attendance at the AGM is free of charge, however we request a contribution of £18 towards our Members' Day venue, buffet lunch and refreshments. You are welcome to bring friends or family with you. They don't need to join as Members, although they will need to register and pay £18 per person towards costs for the day. To book your place, please visit <http://www.pmrzca.co.uk/content/agm2019> or tear off the slip on this page and return it to us with your cheque.



### I would like to attend the Members' Day and AGM on 7 September 2019

Name: \_\_\_\_\_ Member of PMRGCAuk?  Yes  No

Address: \_\_\_\_\_  
\_\_\_\_\_

Tel: \_\_\_\_\_ E-mail:\*

Do you have any access requirements?

(e.g. visual impairment, wheelchair user)

Do you have any special dietary requirements?

I enclose a cheque  I will pay on the day

Please send this form with your cheque to BM PMRGCAuk, London WC1N 3XX.

If you are booking for more than one person, please attach a separate sheet with their details.

\* We will send draft accounts/annual report by email 7 days before the event.



## FAST TRACK SERVICE

Dr Karen Donaldson, Consultant Rheumatologist from NHS Lanarkshire tells us about her recent training, following a grant from PMR GCA Scotland.

"I am a consultant Rheumatologist in NHS Lanarkshire. My colleague Dr Anna Ciechomska, has recently set up a GCA fast track service which I hope to run with her once adequately trained. I was fortunate to receive £1,000 from PMR GCA Scotland which I used to attend the 7th International Workshop in Large vessel vasculitis (LVV), GCA and PMR in Southend in March 2019 arranged by Professor Bhaskar Dasgupta. This was a truly international meeting with expert faculty from Europe and the UK and delegates from as far afield as Australia, North America and Singapore.

We had a series of lectures outlining the benefits of a GCA fast track service and the best way to approach clinical assessment, investigation and treatment of people with suspected PMR, LVV and GCA. An important component of a GCA fast track service is assessment of people with suspected GCA using vascular ultrasound which is a non-invasive and accurate method of assessment reducing the need for temporal artery biopsy. We had approximately 10 hours of scanning time to practise our vascular ultrasound scanning techniques on patients who had GCA and PMR under the supervision of expert faculty. I hope to put all that I



From left: Prof. Dasgupta, Phil Hall and Karen Donaldson

have learned into practise to support and enhance our new GCA fast track service. Thank you all for your support of this vital service."



Karen using an ultrasound scanner to test for GCA

## THE ELEPHANT IN THE ROOM

This was the intriguing title to a Garden Lobby Event in the Scottish Parliament on May 15th. MSPs were invited to meet representatives of the organisations who attend the Cross Party Group on Arthritis and Musculo-skeletal Conditions by Brian Whittle MSP, the Group's Convenor. PMR-GCA Scotland was there flying the flag, or at least displaying our banner.

Joe Fitzpatrick, Minister for Public Health, Sport and Wellbeing, attended and addressed the meeting, after which the meaning of the title became clear in the messages of the two main speakers: Professor Iain McInnes CBE, Muirhead Professor of Medicine; Director of the Institute of Infection, Immunity and Inflammation, University of Glasgow; President-Elect European League Against Rheumatism (EULAR) and Professor Colin Howie, Department of Orthopaedic surgery, University of Edinburgh; Consultant orthopaedic and Trauma Surgeon, NHS Lothian; Past president of the British Orthopaedic association. Our population is ageing, musculoskeletal problems are already the reason for the majority

of consultations with GPs, yet we ignore this when training doctors and allocating resources. Hip replacement is the second most cost-effective surgery done by the NHS, but waiting times have increased significantly. New drugs for inflammatory conditions are available but often very expensive (compare Tocilizumab with Prednisolone) so patients remain on painkillers such as opioids which become increasingly ineffective and likely to produce addiction. Patients, for example the young with conditions like Juvenile Arthritis, young adults with Ankylosin Spondylitis and older ones with osteoarthritis or PMR are all getting a raw deal.

The message being put across was that conditions of the bones, muscles and joints should not be thought of as an inevitable part of ageing, and that nothing can be done for them. Much can, and more should be.



From left: Brian Whittle MSP, Lorna Neill, Chair PMR-GCA Scotland and Dr. Dale Webb, Chief Executive National Ankylosing Spondylitis Society.



HELPLINE

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7 Hamilton Place, PERTH, PH1 1BB

# PMRGCAUK WEEK 18-24 JUNE 2019

Thank you to everyone who took part this year. Just a few highlights from around the UK...

Rosalind Pearman ran a Quiz Night at her local pub in Stroud; Jennifer McIlvenny of the Harrow & Pinner Group ran a coffee morning; Ann Paul organised an awareness raising session at her GP surgery in Birmingham; the Ilkley Group ran a Bring & Buy sale; the Whitstable Group held its first meeting; The Chichester Support Group ran awareness raising stands at a range of venues; Pauline Bain ran 5km every day of the campaign and Margaret Baker of the Plymouth Group ran a coffee morning.



Coffee Mornings in Plymouth



Awareness events in GP surgeries



Sponsored running



Janice Maddock and friends taking part in the Colour Rush.

## WHAT A RUSH!

Congratulations to Janice Maddock, one of the Trustees of PMRGCAUK who raised over £2,000 by taking part in an obstacle race in the summer. Here's the proof...



## TEA WITH 'THE REAL' DOC MARTIN

Are you a fan of ITV's Doc Martin series? This is a chance for you to come and meet the other Doc Martin!

**Dr Martin Scurr** has been medical adviser to the Doc Martin series from its inception and he will be telling us about his role in the series and answer your questions about the series and its future. Martin is also the Daily Mail resident doctor answering the nation's health concerns in his weekly column.

Dr Martin Scurr will be joining members, friends and supporters for tea on Saturday 23 November at the University Women's Club (UWC) in Mayfair.

Details of the event are on the charity's website at [www.pmr.gca.org.uk/content/martin\\_scurr](http://www.pmr.gca.org.uk/content/martin_scurr)

There are 80 places available for this very special event and you can help the team at PMRGCAUK by spreading the word to all your family and friends. This is an open event, everyone is welcome. To book a place or a table to meet Martin and enjoy a scrumptious afternoon tea in the beautiful surroundings of UWC just email [events@pmr.gca.org.uk](mailto:events@pmr.gca.org.uk)

London's Christmas lights are switched on early in November so for those of you who would like to combine the tea with a weekend in London there are special rates on offer for you to stay on Saturday night at UWC. To find out more please email [events@pmr.gca.org.uk](mailto:events@pmr.gca.org.uk)

Closest tube stations: Green Park and Hyde Park Corner

# 3 THINGS YOU CAN DO TO HELP

## 1. COLLECT YOUR STAMPS

When our old stamp dealer retired we lost one of our income sources and while we don't make a lot from stamps, 'Every Little Helps', as they say! Now with a new dealer, we are appealing to you to collect stamps in your Groups or send your stamps directly to:

**PMRGCAUK Stamp Appeal,  
10 Chestnut Avenue, North Walsham,  
Norfolk, NR28 9XH.**

You won't get individual acknowledgment but all funds raised from the stamps are transferred directly into the charity's bank account each month.



## 2. LET US RECYCLE YOUR CARDS

If you don't know what to do with your old birthday and greeting cards and would like to help PMRGCAuk and the environment here is something that costs very little and will make a real difference - donate your used greeting cards and we will upcycle to new.

The PMRGCAuk Christmas card this year will be hand crafted this way, stamped with the name of the charity. The cards will be on sale at our events, including Members' Day. We will not be posting cards this year due to the time involved and the high cost of postage. All cards are individually packed and Christmas cards will be £1 and other cards £1-£2.

If you have cards you wish to donate, please bring them to Members' Day if you are coming. Group Organisers attending PMRGCAuk events will be able to sell cards to their Group members and if Members wish to help by selling cards, please contact Penny by texting 07932 608710 or email [penelope@pmrgca.org.uk](mailto:penelope@pmrgca.org.uk)

## 3. ADOPT AN ORGANISATION

Do you have a local organisation that you know well that might stock our information on PMR + GCA?

Perhaps your GP surgery, a care home, library or community centre? Would you be prepared to talk with them and find out if they could take our leaflets and then make sure they are kept stocked up?

Our 3 leaflets – Symptoms, Information & Support and Join us – have all been updated and reprinted. Get in touch at: [info@pmrgca.org.uk](mailto:info@pmrgca.org.uk)



Earlier tour of the Worshipful Society of the Apothecaries...

## WORSHIPFUL SOCIETY OF SKINNERS

A date for your diary – 6 April 2020 – a guided tour of another wonderful livery company has been reserved for Members, family, friends and supporters of PMRGCAuk.

Email [events@pmrgca.org.uk](mailto:events@pmrgca.org.uk) with any questions and to reserve your place.

More information on both events will be posted on the website or emailed to Members when available.

## YOUR SAY ON EVENTS

We know that for those of you not living within easy reach of London and who are less mobile our events are perhaps a step too far for you. If you have ideas for events closer to home we would love to hear from you. We can't promise to attend your event (but we will if we can!) and although our team is small and run by volunteers we can help you by sourcing likely places, booking venues and with publicity. We are always here to help, so please get in touch by email [events@pmrgca.org.uk](mailto:events@pmrgca.org.uk) or text 07932 608710 (please include your name and contact details in your message).



Are you able to share your story to help other people with PMR or GCA? To raise awareness and fundraise, it helps if people understand the conditions through real stories. If you want to share your journey with us, please contact [candy@pmrgca.org.uk](mailto:candy@pmrgca.org.uk)

# 'IS NANNY ALL RIGHT?'

## A PERSONAL EXPERIENCE

Sue Rolt, 74, diagnosed with PMR in 2012, shares her story with us

I was diagnosed with PMR in 2012 by my GP who prescribed Prednisolone. The initial symptoms went and it then seemed a straightforward matter of tapering-off the dose.

A pain in my jaw that the dentist could not identify subsequently led me to a diagnosis of Temporal Arteritis, more Prednisolone and an introduction to some of its side-effects, e.g. cataracts.

Over 6 years it proved impossible to stabilise the inflammation markers (CRP, ESR) and hence stop the steroids. I declined Methotrexate as a 'steroid sparing' agent and remained stuck on steroids - until I had a PET scan which identified Large Vessel

GCA. This started my journey of discovery of PMRGCAuk and the treatment Tocilizumab (TCZ).

I first came across PMRGCAuk by Googling 'polymyalgia'. Initially I was baffled by the acronyms that seemed meaningless (perhaps the charity could consider changing its name?). I can't easily summarise how much it has helped me – immeasurably would be a start! Through the Telephone Helpline I was better able to understand the situation I was in and the conversations I had led to my interest in TCZ and the role of NICE (the National Institute for Health & Care Excellence) at the time when this new treatment for GCA was being trialed. I had some very helpful conversations with Sarah Mackie, academic Consultant Rheumatologist at the University of Leeds, who is a Patron of the charity, as well as with other Members of the charity, discovering their experiences trying to get TCZ treatment in their area of the country.

TCZ has, for me, been transformational. I didn't realise quite how bad I felt until the cloud was lifted by the treatment. I remember at my grandson's 10th birthday – he asked his Mum, "Is Nanny all-right? She seems very active!" That's because he couldn't remember me being so well! I'm off steroids now and have been using TCZ alone for 6 months. It seems almost all good news although stiffness sometimes returns.

Without the charity, those with the condition would be alone – not knowing where to find help or where to go for support. Their campaigning for better treatment and ensuring patients are well informed is especially important I feel. Keeping yourself informed as a patient is vital to ensure you get the treatment that is best for you. That is why the work of charities like PMRGCAuk is so very necessary.



# JOIN OUR HEALTH UNLOCKED ONLINE COMMUNITY

Are you one of over 2,000 active members on our Health Unlocked forum?

One of the volunteers on the forum, known to many as MrsNails, tells us why it's so important: "The Health Unlocked Forum is a vast source of experience and knowledge which many people find invaluable when newly diagnosed or running into an issue further along in their journey. I volunteered as I have had an eventful PMR journey so felt I had experience and empathy I could share if required. Moderating the Forum is not always an easy task but is essential to keep the content relevant and guiding and assisting Members towards an answer to their question. There are currently three Moderators, each with very different backgrounds and experiences but we work well together as a Team to guide Members through what is sometimes a difficult



MrsNails

and overwhelming diagnosis." Fellow moderator, Yellowbluebell added, "When I was diagnosed back in 2018 with PMR, a disease I hadn't even heard of before, the forum was a lifesaver and provided me with badly needed information. When I was asked by PMRGCAuk to moderate the site, it meant that I could give something back to the forum that helped me last year and still does!"

**PMRGCAuk**  
**HealthUnlocked**

**Join our PMRGCAuk community and make your experience count**

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](http://pmrgcauk.healthunlocked.com)



## VOLUNTEERING OPPORTUNITIES

Did you know that PMRGCAuk only has the full time equivalent of 1.2 members of staff! We rely on the excellent work of our Trustees and volunteers to help us achieve so much! If you are interested in volunteering for PMRGCAuk, we are currently looking for people to help on our Telephone Helpline, to work as Awareness Raising Ambassadors and to join us as Fundraisers. For an informal chat about these roles, please email us initially on [info@pmrgca.org.uk](mailto:info@pmrgca.org.uk)

## WITH THANKS TO..

Catrina Zahoor, who stepped down from her voluntary role in June, had for 2 years been the 'go to' person for many of our Support Group and Meet Up organisers, helping them to keep their web pages updated with local information and to post dates of future meetings. Catrina also encouraged the use of the Give As You Live site [www.giveasyoulive.com](http://www.giveasyoulive.com) which helped to raise hundreds of pounds since we asked members and supporters to use it two years ago – with Catrina also raising almost £500 this way purchasing on behalf of her company. A big thank you from PMRGCAuk!

# 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](mailto:groups@pmrgca.org.uk) or 0300 999 5090.

## NORTHERN IRELAND

### LISBURN MEET UP

Contact: Caroline Stewart  
[pmrgca.ireland@gmail.com](mailto:pmrgca.ireland@gmail.com)

## SCOTLAND

### PMR-GCA SCOTLAND

Contact: Lorna Neill (Chair)  
[www.pmrangca.org.uk](http://www.pmrangca.org.uk)  
[info.scotland@pmrangca.org.uk](mailto:info.scotland@pmrangca.org.uk)  
Tel: 0300 777 5090

## WALES

### CARDIFF SUPPORT GROUP

Contact: Sue  
[cardiff@pmrgca.org.uk](mailto:cardiff@pmrgca.org.uk)

## NORTH WEST ENGLAND

### ILKLEY MEET UP

Contact: Sue  
[ilkley@pmrgca.org.uk](mailto:ilkley@pmrgca.org.uk)

### KENDAL, CUMBRIA MEET UP

Contact: Win Sayers  
[groups@pmrgca.org.uk](mailto:groups@pmrgca.org.uk)  
Tel: 01539 535859

## MIDLANDS ENGLAND

### COVENTRY MEET UP

Contact: Ann Hollingsworth  
[pmrgca.coventry@gmail.com](mailto:pmrgca.coventry@gmail.com)

### EAST MIDLANDS SUPPORT GROUP

Contact: Bridget  
[eastmidlands@pmrgca.org.uk](mailto:eastmidlands@pmrgca.org.uk)

### SHROPSHIRE MEET UP

Contact: Joan  
[shropshire@pmrgca.org.uk](mailto:shropshire@pmrgca.org.uk)

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

## EASTERN ENGLAND

### BEDFORDSHIRE MEET UP

Contact: Lyn/Karen  
[bedfordshire@pmrgca.org.uk](mailto:bedfordshire@pmrgca.org.uk)

### CAMBRIDGE MEET UP

Contact: Trisha  
[cambridge@pmrgca.org.uk](mailto:cambridge@pmrgca.org.uk)

### EAST ANGLIA SUPPORT GROUP

Contact: Sandra Waspe  
[pmrgcaeachair@btinternet.com](mailto:pmrgcaeachair@btinternet.com)

### HARLOW MEET UP

Contact: Julie/Jean/Roy  
[harlow@pmrgca.org.uk](mailto:harlow@pmrgca.org.uk)

### SOUTHEND/CHELMSFORD SUPPORT GROUP

Contact: Pat Fedi  
[southend@pmrgca.org.uk](mailto:southend@pmrgca.org.uk)

### WELWYN GARDEN CITY MEET UP

Contact: Sheila  
[wgc@pmrgca.org.uk](mailto:wgc@pmrgca.org.uk)

### WOODBIDGE MEET UP

Contact: Susan  
[groups@pmrgca.org.uk](mailto:groups@pmrgca.org.uk)

## SOUTH WEST ENGLAND

### BATH MEET UP

Contact: Pat Martin  
[pmrgca.bath@gmail.com](mailto:pmrgca.bath@gmail.com)

### BRISTOL GROUP

Contact: Bridget/Felicity  
[bristol@pmrgca.org.uk](mailto:bristol@pmrgca.org.uk)

### CAMBORNE MEET UP

Contact: Margaret  
[camborne@pmrgca.org.uk](mailto:camborne@pmrgca.org.uk)

### EAST DORSET MEET UP

Contact: Pat Worthington  
[eastdorset@pmrgca.org.uk](mailto:eastdorset@pmrgca.org.uk)

### PLYMOUTH SUPPORT GROUP

Contact: Geoff  
[plymouth@pmrgca.org.uk](mailto:plymouth@pmrgca.org.uk)

### PORTISHEAD MEET UP

Contact: Judith  
[portishead@pmrgca.org.uk](mailto:portishead@pmrgca.org.uk)

### SALISBURY MEET UP

Contact: Patrick O'Donnell  
[pmrgca.salisbury@gmail.com](mailto:pmrgca.salisbury@gmail.com)

### SOUTH WEST (TAUNTON) SUPPORT GROUP

Contact: Wendy Morrison  
[pmrgca.southwest@yahoo.co.uk](mailto:pmrgca.southwest@yahoo.co.uk)

### TORBAY MEET UP

Contact: Trish  
[pmrgca.torbay@gmail.com](mailto:pmrgca.torbay@gmail.com)

## GREATER LONDON, ENGLAND

### GREATER LONDON SUPPORT GROUP

Contact: Anne  
[londonpmrgcauk@gmail.com](mailto:londonpmrgcauk@gmail.com)

### BARNET MEET UP

Contact: Derek  
[barnet@pmrgca.org.uk](mailto:barnet@pmrgca.org.uk)

### HARROW/PINNER MEET UP

Contact: Jennifer  
[pinner@pmrgca.org.uk](mailto:pinner@pmrgca.org.uk)

### HIGH WYCOMBE MEET UP

Contact: Alison  
[pmrgca.highwycombe@gmail.com](mailto:pmrgca.highwycombe@gmail.com)

### ORPINGTON SUPPORT GROUP

Contact: Penny  
[pmrgca.orpington@gmail.com](mailto:pmrgca.orpington@gmail.com)

## SOUTH AND SOUTH EAST ENGLAND

### BRIGHTON MEET UP

Contact: Catherine Spencer  
[brighton@pmrgca.org.uk](mailto:brighton@pmrgca.org.uk)

### CHICHESTER MEET UP

Contact: Patricia Dawson  
[chichester@pmrgca.org.uk](mailto:chichester@pmrgca.org.uk)

### MAIDSTONE SUPPORT GROUP

Contact: Margaret Hicks  
[pmrgca.maidstone@gmail.com](mailto:pmrgca.maidstone@gmail.com)

### OXTED MEET UP

Contact: Debbie Pitt  
[pmrgca.oxted@gmail.com](mailto:pmrgca.oxted@gmail.com)

### PORT SOLENT MEET UP

Contact: Valerie Bidewell  
[pmrgca.portsolent@gmail.com](mailto:pmrgca.portsolent@gmail.com)

### SURREY SUPPORT GROUP

Contact: Shirley O'Connell  
[pmrgca.surrey@btinternet.com](mailto:pmrgca.surrey@btinternet.com)

### WHITSTABLE MEET UP GROUP

Contact: Tom Withers  
[whitstable@pmrgca.org.uk](mailto:whitstable@pmrgca.org.uk)

### WORTHING SUPPORT GROUP

Contact: Christine/Catie  
[worthing@pmrgca.org.uk](mailto:worthing@pmrgca.org.uk)