PMR GCA UK
Polymyalgia Rheumatica & Giant Cell Arteritis UK

£3.50 Free to members

# NEWSWIRE

SPRING 2025
ISSUE 45

## Read the report on Professor Bhaskar Dasgupta's webinar on the GCA-PMR spectrum

## FIND OUT ABOUT THE WEBINARS RUNNING IN PMRGCAUK WEEK!

**Read Sarah's story of PMR and what happened when she reduced prednisolone to zero**

## DR SARAH MACKIE TALKS ABOUT WHY PMR & GCA SOMETIMES REOCCUR

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# Welcome

Spring always feels like an optimistic time of year. The harshness of winter is behind us with the promise of brighter days ahead. I'm feeling similarly optimistic when I look through the contents of this edition. Yes, there are many things that need to be improved for patients – not least speedier diagnoses and more readily available information – and yet there are so many advances being made, both within the charity and within the wider medical community, that we should be reassured we are moving in the right direction.

If you're in any doubt, take a look at the report on Bhaskar Dasgupta's webinar (p.8); at the clinicians busy working on improving understanding and guidelines for patients (p.14); and the clinicians giving up their time to talk to us all during PMRGCAuk Week (p.11).

Working with such a small staff, we owe much of our ability to support patients to our volunteers. Sometimes it's easy to forget this 'army' of people give up their time to help others. When you read about the support group activity (p.4), the story of how the Yorkshire Group evolved (p.6) and how to access the support services we provide (p.9), do take a moment to reflect that these volunteers – whether that's on the helpline, PMRPro or DorsetLady on the forum, or one of our many support group organisers, their dedication to serving others should never be taken lightly.

Fundraising – through your memberships, donations and activities – is the lifeblood of the charity. I'm in awe of Dr Mark Hughes, Consultant Rheumatologist at Royal Cornwall Hospitals NHS Trust who undertook an ultramarathon to raise more money for us (p.3). I'm also looking forward to hearing more about it when he launches this year's Marathon in a Month – our flagship fundraiser for the year. I do hope many of you will join in.

Wishing you a happy Easter and looking forward to seeing you during PMRGCAuk Week.

Humphrey Hodgson

**Humphrey Hodgson**
Chair of Trustees

## FACEBOOK FUNDRAISERS – THANK YOU

After writing about how easy it is to set up a Facebook fundraiser in the last edition – thank you to those who did so. If you have a birthday or important celebration coming up and would like to ask friends and family to donate instead of giving presents, an online fundraiser is the perfect way to do it. If you're not sure how to set one up, details are in the previous edition of NewsWire or you can request a how-to guide from us. Email **info@pmrgca.org.uk**

# CHARITY NEWS

## New Trustee – Professor Margaret Bassendine

We are delighted that Prof. Margaret Bassendine has joined the Trustee Board. She is a long-term member of the charity, with lived experience of PMR, both personally and in her family. She brings a wealth of clinical and research experience, having trained as a physician and liver specialist in London and then moved to Newcastle University for her permanent posts. Her special interests were in the viral disease Hepatitis C, and also in a particular form of liver cirrhosis – primary biliary cirrhosis – which seems to be autoimmune in origin, and in which she made important observations on the genes predisposing to that condition.

She is keen that PMRGCAuk should promote the research agenda, both to the genetic background underlying in families with more than one member with PMR, and the environmental factors that may trigger the condition.

## GCA Awareness Campaign

The GCA Awareness patient group has continued to meet, and we hope to enter the design stage soon with a view to launching the awareness campaign in late summer. Thank you to the patients involved in this who are giving up their time to provide very valuable input.

## An MBE for Professor Bhaskar Dasgupta

Our president, Prof. Bhaskar Dasgupta was recognised with an MBE in the New Year's Honour's list for his services for people with PMR and GCA. In a stellar career which began with studies in India and then at hospitals in the UK, he has a long list of achievements which include being lead and first author of the BSR (British Society of Rheumatology) guidelines for PMR and GCA – the first guidelines in the world to be published for these conditions; developing a fast-track pathway for rapid review and treatment of patients with suspected GCA; lobbying for tocilizumab to be made available to GCA patients and of course his involvement in starting and supporting the two charities, PMRGCAuk and PMR GCA Scotland.

Prof. Humphrey Hodgson said, "Bhaskar has contributed enormously to the recognition, diagnosis and treatment of PMR and GCA, diseases which are often poorly recognised and inadequately treated. As president of PMRGCAuk, the charity supporting and advocating for people with these conditions, he has provided huge support and leadership. We are delighted this has been recognised by this honour."

## Humphrey Hodgson – Chair

Prof. Humphrey Hodgson, Chair of PMRGCAuk, will be stepping down at our AGM in September, having taken up this post in 2018. We are actively looking for a new chair to replace him and will update you with any further news as it develops. If you know someone who might be interested or you would like to be considered for this voluntary position, please contact **sophie@pmrgca.org.uk** for an initial chat.

## Thank you!

There are not enough words to express our thanks and admiration of **Dr Mark Hughes'** fundraising ultramarathon – the Arc of Attrition – he ran in January. Mark kept going over 100 miles through a cold blue-sky day and a gruelling winter night. It took just 29hrs and 38mins (although it must have felt infinitely longer!).

So many of you sponsored him and left encouraging messages which he said helped him to "get through the darkest hours".

Mark raised over £2,500 (and with gift aid this will reach £3,000!). To Mark and everyone who sponsored him, thank you!

(Image courtesy of Truro Group)

# Groups around the country

**Barnet Group** continues to meet every few months at the Cockfosters Bowls Club. For more information of future meeting dates, please email the organiser on **barnet@pmrgca.org.uk**

After their December meeting, the members of the **Chichester Group** went off to the Spotted Cow in Hunston for a very tasty fish and chip meal. It was so enjoyable they would like to do the same again this year. The group also joined with Worthing group for a talk by Dr Menon (see Worthing group for details).

Four new people joined the group in January, and all said they would join in future meetings.

The **Cumbria Group** meets approximately every eight weeks. Its meetings are an informal drop-in chat and coffee style at a local café where they can exchange experiences and information as well as support each other.

On average, six people attend the meetings, a mix of men and women aged 60 or older, with mainly PMR and a couple with GCA. Some are newly diagnosed and some tapering steroids plus one who has 'recovered'.

People are drawn from a wide rural area – eg Carlisle, Lancaster, Kendal areas and from the Lake District and Yorkshire Dales.

Next meetings are on 7th May and 16th July at 10.45 to 12.30 Farfield Mill Café, Sedbergh LA10

Visitors are welcome from other groups!

**East Dorset Group** has grown over the last 12 months from eight members to 36 which is great news but does mean that it is impossible to listen to and "support" everyone. Therefore, they have split into two and created a **West Dorset Group** covering the Dorchester, Bridport, Weymouth, Beaminster and Yeovil area, as it's such a long journey to the Wimborne hub.

Pauline, Tessa and Sally organise and run this group and they have their own gmail contact details. They hosted their first meeting in March.

For specially invited guests both Dorset Groups will join together.

The **Havant Group** is going from strength to strength with excellent support from their local rheumatology department. Colin, the senior nurse matron, has been promoting the group with all PMR and GCA patients. In January they had a gentle physio session with chair-based exercise led by a local physiotherapist. One of their members is currently preparing a welcome leaflet for all new members which contains vital information that they have been grateful to discover since diagnosis. Talks from Arthritis Action and two local rheumatology consultants are also planned for this year.

The recently enlarged **North West & Cheshire Group** met just before Christmas in a new venue, The Cottons Hotel in Knutsford. They had a very festive catch up with a Secret Santa exchange of gifts.

It was so comfortable and welcoming that they also held their February meeting there.

They welcomed several new members to their January Zoom. Their area continues to expand with people from the Wirral, Blackpool & Preston.

Until recently, most of the group's members have been dealing with PMR, but the newest members have GCA.

They have a full year of diary dates ready and are always delighted to welcome anyone who wants to join. Getting together, whether via Zoom or over coffee, is always a very positive experience. To find out more, contact **cheshire@pmrgca.org.uk**

NW/Cheshire group

Pinner and Ruislip group Xmas lunch

The **Pinner and Ruislip Groups** enjoyed a Christmas meal together and have started to think about having their first summer lunch somewhere. They have also talked about doing the 'Marathon in a Month' again this year.

The **Plymouth Group** met up for an informal chat at the Discovery Café in Plymouth city centre in October. Later in December, 11 members and spouses enjoyed a Christmas lunch at the same venue.

In February they met at the Burrator Inn in Dousland on the edge of Dartmoor. There are regular buses from Plymouth to the front door of the inn, good car parking, and a wide range of refreshments. Later in February they were back to the cafe, with lunch and shopping afterwards for those that wanted.

The **Sevenoaks, Tonbridge & Tunbridge Wells Group** continue to meet at their new venue, The Hand and Sceptre pub in Southborough which is much quieter than the previous one and therefore easier for conversation.

The **Truro Group** continues to welcome two new members each meeting. They enjoyed a post-Christmas lunch at the golf club. The highlight of the year so far has been being able to welcome and congratulate Dr Mark Hughes on his huge achievement of running the Arc of Attrition, at their February meeting. See p.3 for more details.

Group organiser, Anne, said, "We are hugely proud of him and very grateful for his support. The race is a huge challenge. Most people take several weeks walking the path, rather than overnight, in the dark and in January!!"

The **Worthing Group** has grown rapidly and now has 26 active members. In December several of its members joined the Chichester group in attending a very informative talk at Bognor War Memorial Hospital by Dr Sanjeev Menon, a consultant rheumatologist, on the diagnosis and management of PMR and GCA. In January they used the links provided by Charon to show both of the September webinars on the cases for and against PPIs and bisphosphonates to charity members who had been unable to view them. The group organiser, Jan, was very grateful to members Phil Cotterell and Mick Watson for enabling these events.

The **Yorkshire Group** has been enjoying their meetings through the long cold winter: the opportunity to get together and talk to people who understand what living with this autoimmune condition is like is particularly appreciated.

Yorkshire has four face-to-face support group meetings, one a month in each location. They also host a monthly Zoom on the third Thursday of each month, inviting those who can't travel. Their two most popular locations are Ilkley (where the group was founded) and Leeds, where the average attendance is 10. At Sheffield and York, the average attendance is four.

Dr Claire Vandevelde attended their January Zoom and gave an excellent talk on bone health with Q&A. More than 30 attended, including participants from Italy and America. Later, in January the regular Leeds meeting room had unfortunately been double booked. Rather than cancel the meeting they were offered the organisation's own training room with an amazing view of the city – see image which was taken by the newest member of the group, Aslaug.

View of Leeds City

## THANK YOU!

**Thank you to the following for volunteering as new group organisers: Jeanette at East Norfolk, Pauline, Tessa and Sally at West Dorset.**

# REFLECTIONS ON ESTABLISHING A SUPPORT GROUP

## by the Yorkshire Group

**In a change with the normal Q&A where we ask a support group organiser about the group they run, Sue Barrass from the Yorkshire group explains how their group came about and developed from two people to 70!**

In 2017 two Sues with PMR met at a PMRGCAuk Research Roadshow in Leeds. We decided to set up a support group as there wasn't one in Yorkshire.

The charity advised us to choose a location close to where we lived – it was important to make the venue as convenient for ourselves as possible, while making sure that others could get there too.

We chose Ilkley, with a station, buses and large town centre car park. We identified a cafe and advertised the first meeting on HealthUnlocked.

Six people turned up for the first meeting. We held subsequent meetings in a community centre with a cafe, and over the years we've used a private room at the rear of a cafe (both free of charge, as long as we eat and drink there) and the local library. We held one meeting in a church room, for which we had to pay, but this was for a talk from a rheumatologist, when we asked people to donate towards the room hire.

The charity set us up with an email address for the group, which means we don't have to disclose our personal contact details. The mailing list has grown over the years to 70!

After a while, some people asked if meetings could be held in Leeds – again with good transport links. John Lewis had a room available to hire free of charge for community groups, and we booked that. We also continued to meet in Ilkley.

Covid changed things and meant that we started to meet via Zoom which continues and is especially useful for people who cannot travel.

Over the years we have offered meetings in Sheffield and York, meeting in cafes within shopping malls.

After about three years, we asked other members of the group if they would be interested in helping to run it. Two others volunteered and Yvonne has taken over the mailing list and has become our main Group Organiser. This has enabled us to continue to support the group without becoming daunted by too large a task. With meetings held in four locations and via Zoom, it could be too much for one person to manage, particularly with health issues of their own.

Over the years, we have met every two or three months, with the inevitable gap due to Covid restrictions. Now, due to the different locations, there is a meeting somewhere in the county every month. Attendance at the various meetings varies from 20 for a meeting with a speaker to sometimes as few as two or three.

The format for most of our meetings is a round-the-table introduction of two minutes each, with any concerns or questions noted down for discussion after the intros. Often, there will be common concerns that others can relate to and can then share their experiences.

### SUPPORT GROUPS

Support groups range in size from just a couple of people to one as large and as busy as this one. They are all vital and allow people to get together and chat with others sharing similar experiences.

If you'd like to find out how easy it is to set up a support group, please email **charon@pmrgca.org.uk**

If you'd like to join the Yorkshire Support Group, please email **yorkshire@pmrgca.org.uk**

# Members' survey feedback

Back in the summer of 2024, we conducted a member survey to better understand your experiences of diagnosis and treatment of PMR and GCA, and your interactions with the charity. We were delighted to receive 729 responses. There were 627 online responses, with a further 102 mailed through the post. We recognise that some of our members are not online, but if you are online and currently only receive hard copy information from us, please consider updating your details with us to also include electronic communication, which will allow us to share information with you quicker and more economically. (You can receive electronic communication and continue to receive a hard copy of NewsWire).

## Who responded?

Responses were broadly representative of our overall membership – 85% female, 15% male – 64% with PMR, 14% with GCA and 20% with both conditions. The age of respondents ranged from 50 to 94 years old.

## What did you tell us?

Answers represented a range of experiences, from very good to very bad, through your diagnosis and treatment journeys but there were strong overlapping themes. It came through very clearly that a large number of people feel they would have benefitted from more information, especially more realistic information, when it comes to how long you can expect to have PMR or GCA, how it impacts your everyday life, and what the tapering journey looks like. For those of you with PMR, a worryingly high number (just over 50% of respondents) were not given information about its link with GCA and what additional symptoms to look out for. For those with GCA it was clear that access to diagnostic testing – ultrasound, temporal artery biopsy, and CT-PET scan – is still inconsistent, and many people are still receiving a diagnosis of GCA without positive confirmatory testing. While none of this information is a surprise to us, gathering it in this way gives us the facts and figures behind the anecdotal evidence we see through our interactions with you in webinars, on the helpline, in support groups and on HealthUnlocked.

## What have we done with the information?

We use the information from our member survey in different ways.

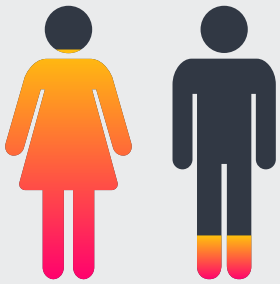
First and foremost, the information helps us to better understand who you are, your experiences of PMR and GCA, which of the charity services are performing well to help you, and which services need to be improved, as well as your experiences interacting with the NHS and other healthcare providers.

Those with GCA may have noticed that this edition of the survey featured more in-depth questions on your diagnosis journey, which will inform our conversations with colleagues in the NHS and Getting It Right First Time (GIRFT) to push for better access to fast-track diagnosis pathways.

Towards the end of 2024, the board of trustees, along with staff, used this information to inform and steer the charity's strategic plan for 2024-2027.

You can read our strategic plan in full on the website soon, along with a more detailed breakdown of some of the information shared in the member survey.

GENDER



FEMALE 84%

MALE 16%

AGE


There were two respondents under 50 and one in their nineties.

**97%**

of respondents felt

**MORE INFORMED**

about PMR or GCA after accessing PMRGCAuk resources or services.

**84%**

of respondents felt

**INCREASING GP AWARENESS**

should be a key priority for the charity.

# Webinar Report

# PMR & GCA: THE ROAD TRAVELLED

**In February we hosted we hosted a webinar by charity president Professor Dasgupta MBE called PMR & GCA: The road travelled.**

Prof. Dasgupta started with a summary of his own professional history and his interest and achievements in the fields of PMR and GCA. He also gave a brief history of how the charity was formed, from the first meeting in 2008 with a group of patients called the PMR Fighters, ultimately leading to the formation of the charity in 2010. It was wonderful to look back on the pictures he shared of their first meeting at the British Dental Academy in 2008, then at the Wellcome Centre in 2010, and reflect on how far the charity has come since.

Prof. Dasgupta talked about the introduction and importance of the GCA Fast Track Pathway, and the Southend GCA Probability Score (GCAPS) in improving the diagnosis pathway for those with potential GCA and, ultimately, the reduction in sight loss that this leads to. We were given an explanation of how both the pathway and Southend GCAPS work. We also heard about the importance of ultrasound imaging, with Prof. Dasgupta talking us through some images of healthy arteries versus those showing the halo sign they look for in a GCA diagnosis.

We heard that not only does the use of the GCA Fast Track Pathway and the Southend GCAPS lead to better patient outcomes, but they also result in financial savings for the NHS. These savings were estimated to be £400 per patient treated for suspected GCA. Perhaps more importantly, when looking at the incremental cost effectiveness (ICER) used by NICE to calculate the cost of implementation against quality of life for the patient, the Fast Track Pathway represented a cost of –£840, meaning it would save money to implement.

Prof. Dasgupta also spoke about GCA PMR Spectrum Disease (GPSD). He said that clinical management of GCA and PMR should be driven by the awareness that they are closely interrelated conditions that form a spectrum of inflammatory diseases which can occur separately, simultaneously, or in temporal sequence to each other. This has been published in several papers and is currently going through a Delphi study to establish consensus and refine definition.

There is already consensus that this spectrum incorporates cranial GCA, ischemic GCA, large vessel GCA and PMR. Prof. Dasgupta is now also working with colleagues in Japan and China to understand if Takayasu arteritis should also be included in GPSD.

Because the subsets of GPSD are not mutually exclusive and can present in different combinations, the stratification of the different conditions is important in determining which treatment(s) should be used for which patient. For example, steroids are still the mainstay, especially with ischemic GCA, but there is evidence that DMARDS provide better outcomes when there is large vessel involvement, and that when GCA is relapsing it benefits from the use of biologics such as tocilizumab.

Prof. Dasgupta's talk was incredibly detailed, covering a lot of information in a short amount of time. If you haven't seen the talk, we would recommend you request the recording by emailing webinar@pmrgca.org.uk as the summary here barely touches on the rich content that was covered.

# How we can help you

## Whether you're new to the charity or one of our long-standing members, there will almost certainly be a point where you need more information or some support.

Typically, a newly diagnosed patient will be looking for information on a condition they've, in most cases, never heard of before. Even someone who's been managing PMR/GCA for a year or longer, may suddenly be struggling with a flare, new or unusual symptoms or just be feeling fed up that "it hasn't gone yet".

We provide support in many different ways so that no matter how someone prefers to access information or make contact with others, there is something to suit everyone.

### Helpline

**0300 111 5090**

If you want to chat through a diagnosis or a sticky patch in your journey or even simply to talk to someone who 'gets' what you're going through, the helpline is available for UK patients. It operates Monday to Friday from 9am to 5pm. The service is run by volunteers and if there is no-one available to take your call, just leave your details and they will call you back. There is a separate number for patients in Scotland **0300 777 5090**.

Thank you to Fiona and all the volunteers who help reassure and provide information to the callers.

### Online forum on HealthUnlocked

**www.healthunlocked.com/pmrgcauk**

The PMRGCAuk forum is 'open' 24 hours a day and allows you to connect with other patients going through similar experiences with PMR and GCA. With more than 5,000 active members on the site and knowledgeable volunteers who answer questions and oversee posts and replies, it's a fantastic source of information and support

Thank you to PMRPro and DorsetLady who give up much of their time to respond to queries and oversee posts and replies.

### Support Groups

**www.pmrgca.org.uk/get-support/groups/**

There are more than 40 support groups across the country – including several in Scotland – as well as some online ones too. A support group is a chance to meet other people navigating the PMR/GCA journey, share stories, get tips and information and feel less alone. Some groups are small, friendly chats while others also invite speakers, run exercise sessions and get-togethers such as lunches. Many people become friends with the people they meet. We would love to have more support groups, so if you would like to join one, but there isn't one near you, do consider setting one up. It's very easy and we are here to help – see Yorkshire groups' reflections on setting up and growing their group on p.6. Details of our groups are on the back page of NewsWire.

Thank you to all our group organisers who set up meetings, welcome people to them and are a friendly face to many.

### Our website

**www.pmrgca.org.uk**

All of the information on this page, along with information about the conditions, information packs, news, videos, charity information, memberships, fundraising, can be found on our website.

**Membership payments and donations help to fund all these services.**

# Launching Marathon in a Month 2025!

## After the success of last year's Marathon in a Month, we are really excited to reveal we are running the campaign again in July 2025.

Not only did we raise much-needed funds and awareness, but we know from feedback how much those who took part benefitted from getting out and walking. While some participants told us how they had to pace themselves, walking on days when they felt well, they were pleased they had done it. We heard about more energy, better sleep, a sense of wellbeing, pride in taking part and a commitment to keep walking afterwards.

Some people took on the whole challenge of walking 26.2 miles over the course of a month. Some joined up with others. The Pinner and Ruislip support group took on the challenge as a group and really enjoyed the camaraderie and friendship of shared walks.

Walks can take place anywhere – around a shopping centre, a local park, the beach, the countryside, getting off the bus a stop earlier or even to the post box and back. A mile is around 2,000 steps.

If you can happily do that or more a day, you would easily be able to take on the challenge. Whereas if you're less confident, split the steps with a friend, a relative or your support group.

We would love to see more members and support groups take part this year. We would also love to raise awareness in local press about people's involvement – we can provide a press release for people/groups to send out. It's a brilliant way to let people in the area know about the charity!

Fundraising is vital to keep the charity and all its activities going – from the helpline to support groups to our forum on HealthUnlocked. Without funds, without a charity, these services simply would not exist. Our slogan for this campaign is Keep Going to Keep Going!

Last year we raised £11,000 (including gift aid) and this year we're raising the bar and hoping to smash £16,000!

Whether you can raise £50 or £500, just like the steps for a walk, the pounds add up and between us, we can raise money to keep going.

## How to get involved?

We are hosting a launch webinar in June. Consultant Rheumatologist, Dr Mark Hughes will be giving a talk on exercising with PMR and GCA. Many of you will know him as the rheumatologist who recently completed the gruelling Arc of Attrition to raise money and awareness for us. He'll also be able to tell us about the inspirational challenge he took on (see p. 11).

1. Join in the webinar on Thursday 12th June at 11am. If you can't make the date, sign up for a recording.
2. Let us know you're planning to take part – we'd love to hear from you. We can also send you a bullet point list of things to help get you started.
3. Sign up with a JustGiving page or request sponsor forms – we can supply a "how-to" guide for both.
4. We can also send out a promotional post to share on your social media pages, email footer to add to your emails, and a press release template to edit for your local press.

"On the days I walked, the uplift in my mood was noticeable. I had found a new focus and purpose which continues today."

A MILE IS APPROX 2,000 STEPS!

COMPLETE THE CHALLENGE WITH A DAILY 20 MIN WALK!

KEEP GOING TO KEEP GOING!

# PMRGCAuk WEEK!

**We are hosting two webinars during PMRGCAuk Week, which runs from 23rd to 29th June this year, and will be launching Marathon in a Month with a webinar earlier in June.**

### Exercise with PMR/GCA and launch of Marathon in a Month

*Thursday 12th June at 11am GMT*

**Dr Mark Hughes**, Consultant Rheumatologist at Royal Cornwall Hospitals NHS Trust

Mark will talk about what happens to your muscles when you are on steroids for PMR/GCA and how exercise can help. He will also talk about his own personal challenge running over 100 miles to raise money for us.

### The Challenges of Diagnosing and Managing PMR in Primary Care

*Tuesday 24th June at 11am GMT*

**Professor Toby Helliwell**, Professor of General Practice and Primary Care lead in Global Health, Honorary Professor of General Practice Midlands Partnership University NHS Foundation Trust

A GP by background, Prof. Helliwell has focused his research career on PMR and GCA in general practice. As this is where people with PMR and GCA are first seen and often managed, he feels it is essential that the research can contribute to better and earlier diagnosis by GPs and to support people with PMR and GCA through the course of their illness.


### Sight loss with GCA – Why does it happen? Who's most at risk? What should you know?

*Wednesday 25th June at 11am GMT*

**Professor Susan Mollan**, Honorary Professor at the University of Birmingham and a Consultant Neuro-ophthalmologist

Prof. Mollan will describe sight loss in GCA. She will discuss why it happens and who are the people that may be at higher risk of developing sight loss. Importantly she will discuss sight changes that you may experience from treatment for GCA. She will provide helpful advice on what to do, should you be concerned about your sight.

Prof. Mollan has a keen interest in how GCA affects the eye and the brain. She actively works to provide guidance for clinicians and these include the European League Against Rheumatism GCA guidelines (2019); British Society of Rheumatology GCA guidelines (2020); the European Headache Federation GCA guidelines (2020). She is currently part of the European Alliance of Association For Rheumatology task force for PMR and Large Vessel Vasculitis 2025 guidelines. She works with the Royal College of Ophthalmologists to support the National Institute of Health and Clinical Excellence for scoping consultations and technology assessments for new treatments for GCA.

Registration for the webinars will open in May and will be by email to **webinar@pmrgca.org.uk**

Webinars are open to everyone and donations will be gratefully accepted.


## A WEEK TO RAISE AWARENESS TOO

Please also look out for and share posts on social media during PMRGCAuk Week. Every post liked, commented on and shared, helps to make more people aware of the charity and the conditions of PMR and GCA. This might help someone get a speedier diagnosis or to find our charity and get support. It might help you to find someone you know who also has one of the conditions but has never mentioned it.

## A Rheumatologist Explains...

# Why does PMR/GCA sometimes come back?

**A member wrote to explain about the frustration of recovering from PMR/GCA only for it to return some years later.**

Dr Sarah Mackie
Consultant Rheumatologist

**"After experiencing a lot of muscular pain for over a year, I was diagnosed as having PMR in the summer of 2012 and then GCA in the autumn. Over two years, as I gradually reduced the prednisolone, I had flare-ups and so had to increase the dose. In 2014, the consultant suggested I try methotrexate as a boost to the steroids. At last something worked, and by 2016, I was off the steroids, on 5mg of methotrexate and pain free. By 2018, I was even off methotrexate. I thought I was cured, until February 2024 when I woke up with a very stiff neck and pains in my head – GCA was back."**

Many patients with PMR and GCA tell me that their ultimate dream is being able to stop all their medications. But if the symptoms return some years later, what does that mean? Does it mean the disease never truly went away? Or can you get it twice – I seem to catch a cold every Christmas holiday, but that's probably a slightly different cold each time. On the other hand, some infections, like chicken-pox, never really go away – instead, they go into hiding, and have a tendency to pop up again years later in the form of shingles.

Some diseases are viewed as something external to the body, an unwelcome visitor that will eventually leave us; other diseases are viewed as a dysregulation of body systems – what doctors call a chronic (long-term) disease. Sadly, we're not like starfish, able to grow a whole new limb on demand. As children, we learned that cuts and bruises we'd get in the playground would seemingly heal perfectly, but even this apparent superpower works less well as we get older.

Given the intricate interplay of the immune system with every other body system, I think it's a mistake to consider PMR and GCA as temporary visitors, gone after a year or (mythically) two. In my mind, PMR and GCA are chronic diseases. Many studies have shown that those giant cells can hang around a very long time, even when the disease looks as if it has "gone away".

The inflammatory state of PMR/GCA is like an unbalancing of a dynamic system that normally exists poised in perfect balance. Signs of inflammation are the end-result, but they aren't the underlying cause. Treatment with prednisolone reduces inflammation and prevents certain disease complications, but it also pushes the body's systems into a new, subdued state that can be hard to exit from. Transitioning from feeling-ok-on-steroids to being-ok-off-steroids can be a bumpy road, and may necessitate a very slow steroid taper. You mention how well methotrexate seemed to work for you: it might not just quell inflammation, but for some, it might also help to re-stabilise the immune system, reducing the risk of relapse during and after steroid taper.

This might seem as if I'm saying that there is no hope of recovery. Far from it! The sheer complexity of the immune system, and its links with every other body system, means that if other medical conditions are managed well, this can make treating PMR/GCA more straightforward. Complementing the treatments recommended by your doctor, diet and exercise, healthy relationships and effective stress-management can make a huge difference for many with PMR/GCA. Doctors might not be able to entirely prevent PMR/GCA from relapsing, even after six years off all treatment, but if relapse does occur, health professionals can be there to advise and support you once again, with personalised, evidence-based medical advice.

Sarah Mackie

**Dr Sarah Mackie**
Consultant Rheumatologist

If you have a question for Dr Sarah Mackie, please email **letters@pmrgca.org.uk**. For ethical reasons, Sarah can't give medical advice or discuss individual cases.

## MEMBER'S STORY:

# A FORCED TAPER TO ZERO MADE ME ILL

Sarah (67) from North Hampshire shares her story of PMR

In July 2019 (aged 62) I had a bad fall onto my coccyx, and although there was no fracture, it was very swollen. Five weeks later, my right hip began to hurt and then I started getting muscle stiffness in the morning. It became so bad, I felt as if I'd run a marathon the day before, and I had to use my arms to lower myself onto the loo.

My GP suggested blood tests. From the results, he explained that I might have PMR as my ESR & CRP were raised. I also had an abnormal liver function test but this has settled down since beginning PMR treatment. I started on 15mg of prednisolone that evening – then continued taking it every evening as no one told me (until 2021!) it should be taken in the morning. My GP referred me to a rheumatologist for ongoing care.

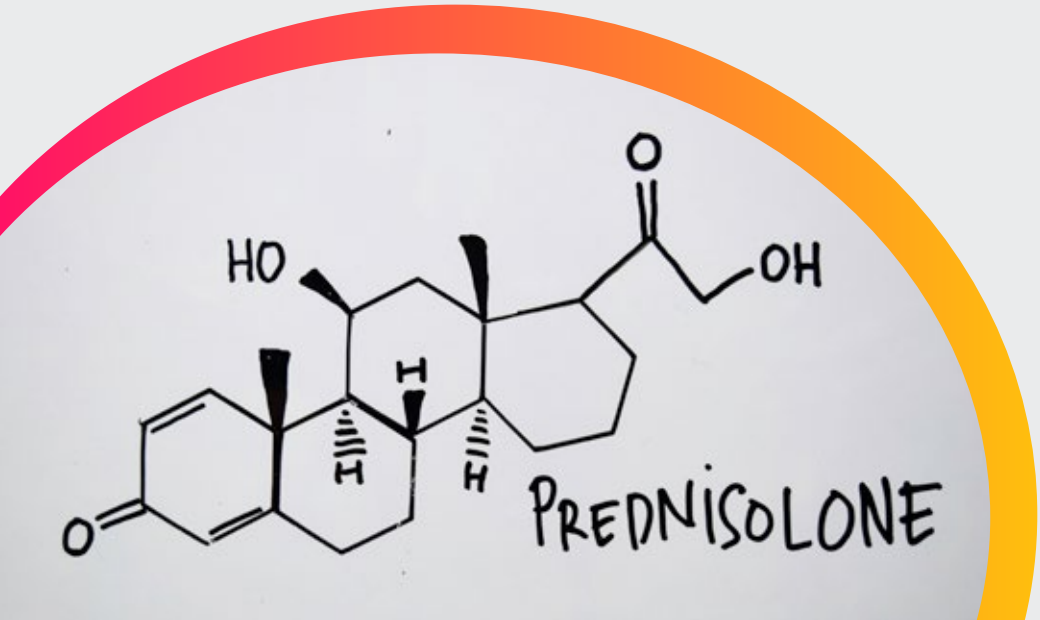
Tapering has had its ups and downs. When I got to around 7mg of prednisolone, my symptoms started to return. I had pneumonia and pleurisy in 2021 and was hospitalised. My steroid dose went back up. My iron levels dropped and I now take Ferretin twice daily. I had a DEXA scan early after my diagnosis and results showed I was just in osteoporosis. After lots of calcium tablets and the bisphosphonate, risedronate, I am now classed as having osteopenia. I keep very active: walking, pilates, tennis, gardening – trying hard to keep fit.

In 2023, my rheumatologist insisted that I reduce to zero prednisolone, stating the pain I was experiencing again was steroid myopathy – not a return of PMR. Over the next 18 months, I became steadily more ill. At the worst point, I contacted the Help Desk provided by the local rheumatology department and the "enlightened" rheumatologist who answered my call sent me for an emergency PET scan which confirmed I had PMR and also requested a Synacthen test to see if my adrenals were working or not.

Meanwhile, the original consultant put me back on steroids, reassuring me that this would not prevent me from having the Synacthen test. Sadly that was incorrect and I am unable to have the test until I get below 3mg.

Being back on prednisolone, I feel like a new woman! I have so much energy. After my "steroid myopathy" I have changed consultant and now see the "enlightened" rheumatologist who was so helpful previously.

I was grateful to find the charity when I was going through the difficulties of the misdiagnosis. I'm a lot more knowledgeable about the condition now than I would otherwise have been. The forum on HealthUnlocked has also been brilliant for answering my questions and helping me to find information.




**Are you able to share your story to help other people with PMR or GCA?**

Please contact **fran@pmrgca.org.uk** or call 0300 999 5090 if you can help.

# RESEARCH AND DEVELOPMENTS

## Access to ultrasound for GCA diagnosis in England and Wales

Following the Freedom of Information (FOI) request we submitted to English health boards about access to ultrasound for GCA diagnosis, we wrote to Dr Lesley Kay, National Clinical Director for Musculoskeletal Conditions, NHS England and National Clinical co-Lead Rheumatology, Getting it Right First Time (GIRFT), about our concerns about delays in diagnosis of GCA. We included two patient stories to illustrate the potential consequences of delays. We now have a meeting with Dr Kay to discuss this further.

Our thanks to Margaret and Ishobel who shared their stories of delayed diagnosis of GCA and subsequent sight loss.

We have made a similar FOI request to the Welsh health boards asking about access to both ultrasound and temporal artery biopsy.

## BSR PMR guideline update

Dr Max Yates and Dr Sarah Mackie are co-leads for the BSR PMR guideline update with Deputy Chair of PMRGCAuk, Janice Maddock as one of the patient experts involved. The guidelines are usually updated as and when they need to be, based on new evidence as it arises, but usually within five years or so. The PMR guidelines haven't been updated since 2010, so are long overdue. More information is available at **www.pubmed.ncbi.nlm.nih.gov/38371294/**

The aim is that the guideline will be published in Jan 2026.

## Improving health professionals' knowledge of PMR

Dr Anne O'Brien, Senior Lecturer in Physiotherapy at Keele University, has started an international "community of practice" to start to address improving health professionals knowledge of and understanding about PMR.

She said, "There is growing recognition that there is a gap in some health professional's knowledge about PMR. Students are not always taught a lot about PMR and because of the relatively infrequent times health professionals will meet people living with PMR, practising nurses, allied health professionals and doctors may not always recognise the early signs and symptoms as PMR."

Participants attended the first online meeting in January from the United States, Ireland and the UK with representatives from PMRGCAuk, the US Vasculitis Foundation as well as health professionals and academics. Others from Australia and Tasmania have also expressed interest in participating in this group. More information will follow as the group evolves.

## Next steps after PMR Paradox project

As the PMR Paradox project comes to a close, Dr Sarah Mackie has been holding a series of meetings to discuss the current situation in PMR and to think about what productive partnerships between patients, clinicians and researchers might look like. More details will be in the next edition.


## Update on Polymyalgia Rheumatica and Giant Cell Arteritis: A Survival Guide

The third edition of Kate Gilbert's popular book is underway. Dr Vanessa Quick, consultant rheumatologist and trustee of PMRGCAuk, is on board as co-author. The book will still be written from the patient's point of view, and Vanessa will have sections where she will be able to put her own perspective as a practising rheumatologist.

Kate is now back on HealthUnlocked to learn from patients and is hoping to visit a few support groups in the spring.

## PMR Paradox patient videos

In the last edition of NewsWire we mentioned the videos that have been produced as part of Lucas Coutin's work exploring barriers to diagnosis. These are now up on our website at **www.pmrgca.org.uk/people-with-pmr-share-their-video-stories/**. We've had great feedback on them so do take a look.

Helpline
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Pmr Gca SCOTLAND

# Notes from the Chair – Richard Cuthbert

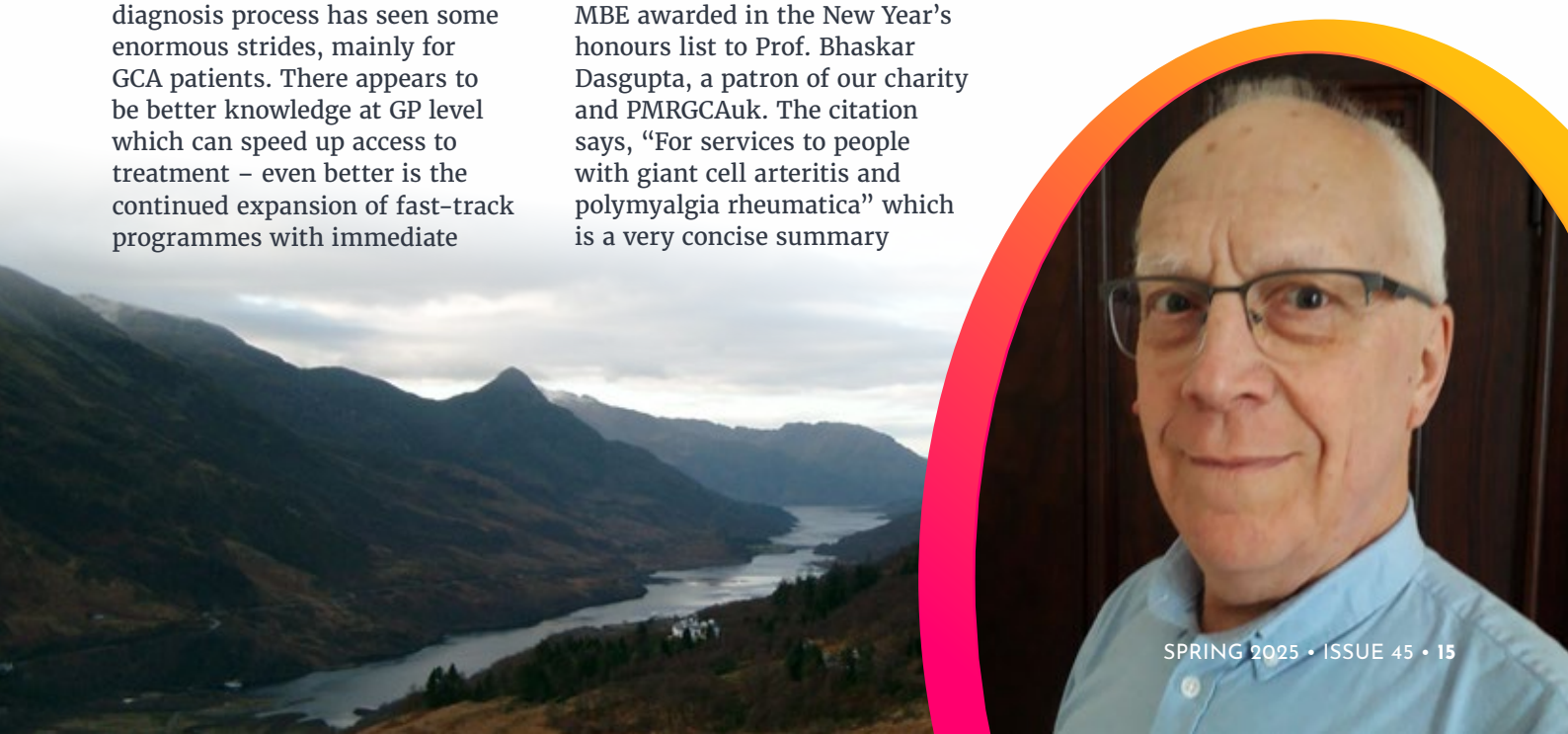
**February 2025**

It is a pleasure to report on a special birthday celebration in Dundee during December. There was a party to mark Jean Miller's 90th birthday with a gathering of family and friends enjoying good company and hospitality. Back in 2006 Jean founded the Scottish charity in response to the absence of patient support when she was diagnosed with GCA. She initially formed a support group in Dundee and we have grown from there to establish further groups in Aberdeen, Edinburgh, Glasgow and the Highlands group based in Inverness. In typical fashion, Jean issued a no-presents rule for the party but instead donations could be made to the charity. We did however send some flowers, and I was also delighted to forward a kind message of birthday greetings from Humphrey Hodgson, Chair of PMRGCAuk.

It is nearly twenty years since circumstances inspired the formation of the charity – think about what has changed in that time, and also what hasn't. The diagnosis process has seen some enormous strides, mainly for GCA patients. There appears to be better knowledge at GP level which can speed up access to treatment – even better is the continued expansion of fast-track programmes with immediate medication and access to scanning for confirmation purposes. Sadly the diagnosis process for PMR seems to remain a bit of a lottery, dependent on previous experience of each GP. I get the impression, however, that younger GPs are coming out with more taught knowledge, which can only be good. On the treatment side there is also a combination of new and old. Good old prednisolone is still the workhorse drug – it seems to be saddled with a bad name online, but is extremely effective and cheap. Where prednisolone is not suitable, there is now an ever-widening range of alternatives. I am not knowledgeable about the different characteristics but at support groups and in reading material there is more frequent mention of methotrexate, leflunomide, tocilizumab and others. Our little-known conditions are getting more and more attention as the years go by – long may that continue.

More congratulations were in order when we learned of the MBE awarded in the New Year's honours list to Prof. Bhaskar Dasgupta, a patron of our charity and PMRGCAuk. The citation says, "For services to people with giant cell arteritis and polymyalgia rheumatica" which is a very concise summary for a vast portfolio of work with patients and in research studies looking at causes and treatments for these conditions. I will keep it concise and understated too – Congratulations and thank you, Bhaskar.

After too long a pause I am pleased to report that we have revived our financial contributions to training and research. From a base in Glasgow, Prof. Neil Basu is involved in many projects with links to PMR and GCA. In this project he plans to look at the relevance of B cells (the immune cells which produce antibodies) in the blood of GCA patients. This is a new area and, in the future, could lead to different therapeutic approaches for people with GCA, potentially replacing steroids. Our small donation can contribute to the cost of laboratory consumables for a research student. Not only can this help with scientific knowledge, but it might influence the career of a future clinical academic (and persuade them of the importance of GCA!).



Our network of groups around the country is growing!

# SUPPORT GROUP CONTACTS

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