PMR GCA UK
Polymyalgia Rheumatica & Giant Cell Arteritis UK

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NEWSWIRE

SUMMER 2025
ISSUE 46

Learn about steroids and the adrenal glands

READ WARREN'S STORY OF PMR AND GCA

Updates on research and developments

DR SARAH MACKIE TALKS ABOUT THE USE OF DMARDS

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Welcome

I'm not sure there is ever a quiet spell here at the charity, but the last few months have certainly been busy. We've seen the resignation of our Director, Sophie Boyce – which is a loss for us all and we wish her well – and the appointment of her replacement, Janette Mannell, who brings fresh ideas and much experience to the post.

We hosted three webinars during PMRGCAuk Week and launched Marathon in a Month.

A thank you to the clinicians who made those webinars possible and to all the researchers and rheumatologists whose work and dedication to understanding and improving the lives of those with PMR and GCA continues to drive progress. While this can seem frustratingly slow at times – for them as well as you, they are the stepping stones to change. Their efforts (see p.12), and of the patients who get involved too, are hugely appreciated.

Dr Vanessa Quick's highly informative article on steroids and the adrenal system (p.8), with its clear explanations, is a must-read for anyone navigating long-term steroid treatment.

Throughout this edition, there are reminders of the incredible support from our fundraisers too. It's no exaggeration to say the charity would not exist without them. Not just those taking part in Marathon in a Month – which was just about to begin as we prepared this edition – but the people leaving gifts in wills, and families raising funds in memory of loved ones. You have our deepest gratitude.

Finally, this issue marks my last as Chair of PMRGCAuk. It's been a privilege to help shape the charity and these pages. I leave the charity and NewsWire in excellent hands, and I look forward to seeing how it grows in the editions to come.

Humphrey Hodgson

Humphrey Hodgson
Chair of Trustees

IN MEMORY OF KOALAJANE

Jane Dinneen was an active member of the charity who fundraised, raised awareness, and was known and loved on HealthUnlocked as KoalaJane. She passed away following complications from surgery in April. Her family set up a JustGiving page, which was supported by many charity members as well as HealthUnlocked members and many memories were shared on our forum. Thank you to her family for raising over £1,900 – a wonderful legacy for Jane who was always happy to help people with PMR and GCA. **https://healthunlocked.com/pmrgcauk/posts/152007935/in-memory-of-koalajane**

All information in this magazine is for informational purposes only and is not a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your doctor or other qualified healthcare provider regarding your own medical condition or treatment. Never delay in seeking medical treatment because of something you may have read in this magazine.

CHARITY NEWS

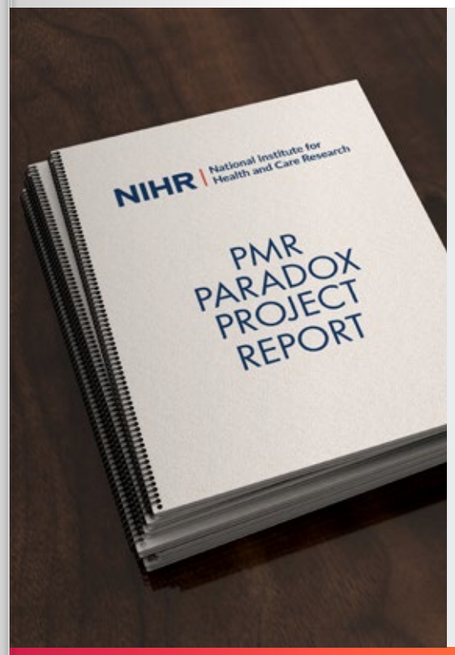
Farewell to Sophie Boyce

In September, we say goodbye to our charity director, Sophie Boyce, who joined in August 2023. Sophie started a new job in May but has continued to work reduced hours during the summer to help create a seamless transition for her replacement.

During her time with us, she oversaw the launch of the exercise booklet, *Maintaining Movement, Activity and Exercise with PMR: A Self Help Guide*, following Anne O'Brien's research with Keele University and the University of Leeds. This was the conclusion to a project funded by a donation from one of our members. Sophie was also the charity lead on the PMR Paradox project which has recently concluded.

Reflecting on the two years, Sophie said, "It was also a privilege to attend the consensus development meeting on the GCA-PMR spectrum, chaired by our President Professor Bhaskar Dasgupta, and speak about the work of the charity.

"I have immensely enjoyed my time with PMRGCAuk. When I started, I had no idea what amazing people I would be working with – staff, trustees, volunteers, members and so many others. I have learnt so much from all of you about the conditions and the huge impact they can have on people's lives, and I share the frustration that they aren't more well known. I'm sad to be leaving but confident that the charity will be in safe hands with Janette."



PMR Paradox

The PMR Paradox Project came to an end in March. At the time of writing, the final touches are being made to the NIHR report. The report will be published and made available to members – possibly before this edition of NewsWire reaches you.

For now you can read a little more in this press release: **https://leedsbrc.nihr.ac.uk/2025/06/09/i-thought-i-was-just-getting-old-new-research-reveals-inequalities-in-polymyalgia-rheumatica-care/** and in a letter from Dr Sarah Mackie to the BMJ **https://www.bmj.com/content/389/bmj.r561/rr-1**.

Charity Strategic Plan

Our strategic plan for 2024-2027 is now available on our website at **https://pmrgca.org.uk/about-us/what-we-do/**

Welcome to Janette Mannell

We are delighted to introduce the new director, Janette Mannell, who is looking forward to making a positive contribution to the charity and the work that we do. She has spent most of her career working in the voluntary sector, for both small and large charities, including the National Deaf Children's Society, Mencap and Guide Dogs for the Blind, managing operations and support services. Prior to that, she worked as a speech and language therapist, both in health and education.

Janette said, "My motivation has always been trying to make a positive impact on individuals and families, and I am committed to ensuring that those who need it receive good clear information, support and advice during vulnerable and complex times. I see this as a really exciting opportunity to make a difference to the lives of individuals affected by PMR and GCA. Making a difference to the people that I work for has always been the cornerstone of what I have tried to achieve in my working life and this role will enable me to continue that commitment."

"I'm very much looking forward to getting to know you over the next few months and working alongside you to continue to deliver and develop services, information and support that meet your needs."

On a personal level, Janette has spent six years living in Provence in the south of France, returning to the UK in 2024. She enjoys being outside in nature and particularly loves being by the sea and walking on the beach with her dog.

Groups around the country

High Wycombe group

Barnet group has had several meetings this year, with two of them exceeding 10 attendees, where they covered experiences of prednisolone, rheumatologists and pill splitting. Their next meeting will be held in mid-October but is yet to be confirmed.

Brighton group continues to thrive with 15 members and bi-monthly meetings with the option of face to face or Zoom.

Chichester group has had three women join who have several health problems as well as PMR/GCA, so Marathon in a Month wasn't an option for the group but they are sending in a donation. The organiser has found a better room for their meetings and this has proved successful.

Since splitting from West Dorset, the **East Dorset** group is flourishing with new members joining and they can now give more time to support everyone.

Last month they had a discussion exchanging information about the different costs of travel insurance and a member gave a short talk on wellbeing.

Their local Consultant Rheumatologist Dr. Khurshid who is supportive of the group, attended the July meeting. They are hoping to invite a pharmacist to a future meeting to better their understanding of specific medications and how they interact.

They plan to have a Christmas lunch in November at the Garden Centre.

Great Yarmouth & Lowestoft group consists of 11 members, with 2-3 active group organisers. They held their first meeting in March at which Consultant Rheumatologist Dr Makkuni gave a slide show, followed up by a meeting in June with Q&A with him. The next planned meetings are for 10th September and 10th December. The meetings are held at the James Paget Hospital grounds with tea, coffee and biscuits provided. They are hoping for a future talk on the importance of exercise with the yoga teacher of one of the organisers.

They have distributed posters (supplied by Charon) to GP surgeries, the library and Age Connected to promote the new group hoping to encourage new people to join. Age Connected advised that they have several people with PMR/GCA who attend their facility and offered a room upstairs to host a coffee morning. There is a lift in the premises for those unable to use stairs

They have also created a Facebook page so that people can find them easily.

Over 40 members have joined the **Havant** group since its setup in May 2023. There is a regular core number of 15 to 20 attendees, with several members opting to maintain contact electronically so they are informed of visits and talks.

Colin Beevor, Senior Nurse Matron, from the local rheumatology department maintains constant support for the group. He has arranged various practical sessions including information about osteoporosis and exercise with PMR & GCA. In addition to these, two of the department consultants have shared valuable up-to-date information about current research and treatments with invaluable Q&A sessions afterwards.

High Wycombe group continue with meetings on the second Wednesday of each month at the Riverside, High Wycombe. They have three new members, two with GCA and one with PMR.

Maidstone group has welcomed new members this year. Discussions on their experiences have covered everything from steroid tapering, managing fatigue and pacing, the effect of medication on the adrenal glands and the HPA axis, as well as tips about not eating liquorice while taking prednisolone – because it can increase the amount of steroid in your body – and how to add medical information and emergency contacts to a phone's locked screen.

In May they had a presentation on home fire safety awareness from Kent Fire & Rescue Service, which included details of the free home Safe and Well visits available for customers who may have particular needs or priorities, including living with long term medical conditions.

Northwest and Cheshire group held a very special meeting in May where they hosted Dr Kate Gilbert who wanted to conduct some research for the latest edition of her forthcoming book. Kate is co-authoring Polymyalgia Rheumatica and Giant Cell Arteritis: a survival guide with PRMGCAuk trustee Dr Vanessa Quick. It was a busy session with 16 attendees. Kate was interested to hear that there are noticeably more members in the group with GCA. They discussed what had and hadn't changed since the last edition (2016). Covid, in particular, got a mention, and they covered additional health issues such as diabetes and heart problems. There were several volunteers to review the first draft when it's ready.

In June they met at RHS Garden Bridgewater for a face-to-face meeting which was also the launch walk for their Marathon in a Month.

Pinner and Ruislip had a speaker from Age UK who spoke about the services they offer and about benefits that they can help people to claim. Discussions over the last year included issues such as the importance of keeping moving, tapering, adrenal insufficiency, sick day rules and varying levels of support from GPs. They celebrated a member's 95th birthday earlier in the year (see image) and enjoyed their first Summer Lunch in July as well as completing Marathon in a Month.

Joan Celebrating 95th

Sevenoaks, Tonbridge & Tunbridge Wells group continue to meet every other month for informal chats which they find really help, as wider friend and family groups have little awareness of, and do not understand, their illness.

Shropshire group meets regularly in the community room in Tesco Extra, Shrewsbury. Recently they discussed new research and moves to rename PMR and GCA (and LVV) to GPSD. This is an acronym for Giant Cell Arteritis and Polymyalgia Rheumatica Spectrum Disease. All of which, it is proposed, should be treated as part of a spectrum of the same disease.

They hope to arrange special guest speakers or an activity for future meetings and welcome suggestions – please email them on **shropshire@pmrgca.org.uk**.

The recently formed **West Dorset** Group meets monthly in the PIP Poundbury Café meeting room from 11:00 to 12:30 followed by lunch. The room costs £10 per hour and is currently being privately funded but the group will need to find funding for it in the future. Eleven people attended the first meeting in March, fewer in the following meetings, and they are working to get the word out about their group. There will be no meeting in September. After that they plan to continue meeting monthly, occasionally getting together with the **East Dorset** group for meetings with their local Consultant Rheumatologist, Dr Khurshid, from Poole Hospital.

People come to the meeting from the Bridport, Yeovil, Beaminster, Weymouth and Dorchester areas. With two group leaders – Tessa and Pauline – they are all finding companionship and support from each other and are appreciative of the support from DorsetLady who has volunteered on HealthUnlocked for many years and is a wealth of information.

Many in the group have GCA so they can swap stories of being on high levels of prednisolone. Top tips include: "do not do a big house clear out with all that extra energy because you may get rid of things you need!" and to stay away from online shopping and "buying things you don't need"!

Whitstable group meetings usually attract about 11 members. Meetings have included a seated exercise session, a discussion on the PMRGCAuk forum on HealthUnlocked which opened up a whole new range of topics and possibly attracted some new members. In April they watched a recording about stomach protectors (PPI) and in May enjoyed an Active Body Active Mind class with guest speaker, Lou Arnold. This focused on improving balance, strength & coordination.

Yorkshire Group has attracted quite a few new people this year and had eight meetings around the county covering their four locations. In May they added Doncaster which meets in a cafe like the York and Sheffield meetings.

Members of the group have been involved with the PMR Paradox Project, which came to an end in March.

They held a Zoom session about diet and steroids in April which was delivered by one of the joint leaders, Teresa Cook. It attracted many people from outside the group and was well received. There will be a follow up meeting in the coming months.

The Zoom meeting continues on the third Thursday of each month at 11am–12.30pm for those who can't travel or who live in remote areas. Anyone can join in regardless of post code. Email **yorkshire@pmrgca.org.uk** for the link.

THANK YOU!

Thank you to the following for volunteering as new group organisers: Yvonne at New Forest, Lucille at Great Yarmouth and Lowestoft and Maxine at Birmingham.

Spotlight on Group Organisers

Penny Denby, WedPM Zoom

Condition:
I have had PMR since the beginning of 2013, now taking 3mg prednisolone daily. My mother had GCA and PMR for over 30 years.

How many people typically attend meetings?
Between eight and 20 and occasionally more!

How often do you meet?
Monthly, on the fourth Wednesday at 3pm

What is the format of the meetings?
Meetings are similar to the face-to-face meetings. Everyone shares their experiences, tips and advice. Even first-time attendees find the meetings so friendly and enjoyable, as well as interesting, that they join in. In the past, we have had talks from professionals including a St John's Ambulance resuscitation talk and 'live' demonstration – which is a challenge across Zoom!

Why did you decide to set up/take over a group?
As a past chair of PMRGCAuk, I knew there was a gap in supporting those with PMR and GCA who do not have a local group; some are housebound, so an online group is a perfect opportunity to get together to share information and experiences. During the covid pandemic, more and more people were using online communication platforms like Zoom and WhatsApp so it was the perfect time to set up a Zoom group.

How much time does it take?
The monthly meeting started off as a one-hour session but usually overruns. In May, Yorkshire group organiser, Teresa Cook, and PMRGCAuk member Jackie Behar, did an excellent presentation on steroids and weight gain; with a Q&A session we were on-line for three hours!

Admin for running the WedPM group and my Orpington Support Group takes about two days a month.

Does anyone else help you?
I am very fortunate that Sue Chandler ('DorsetLady' on the charity's HealthUnlocked forum) brings all her expert advice to attendees, and several group organisers, Anne Smedley (Whitstable), Christine White (Maidstone) and Teresa Cook (Yorkshire) are also on hand to share their knowledge.

If anyone would like to help with admin, emails and/or managing the meetings, I would love that!

> "I really enjoyed your talk yesterday and your many good suggestions, how to work with the Keto diet to curb steroid-induced weight gain."
>
> **WedsPM group member**

If you'd like to join the WedsPM Support Group, please email wedPM@pmrgca.org.uk

Online support groups are also run by the Northwest & Cheshire and Yorkshire groups – for more information see https://pmrgca.org.uk/online-support/

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

Members' Day 2025

Our AGM and Members' Day takes place on Saturday 6th September 2025 at 11am

We have two fabulous speakers lined up who will be talking about the of imaging for PMR and GCA. There will be time for Q&A after each talk.

Talk 1: The role of imaging in revealing the cause of PMR symptoms
by Dr Claire Owen a clinician-scientist rheumatologist from Melbourne, Australia who completed her PhD on polymyalgia rheumatica with a specific focus upon PET/CT imaging applications in 2020.

Talk 2 The role of imaging in GCA diagnosis and monitoring
by Professor Bhaskar Dasgupta MBE, Consultant Rheumatologist and President of PMRGCAuk

If you haven't already booked your place, please email **webinar@pmrgca.org.uk**

The Zoom link will be sent out in early September.

CAN YOU HELP?

Due to illness and other circumstances, our helpline is down to just four volunteers, and we are having to consider cutting back the service.

- Are you good at listening?
- Have you got lived experience of either PMR or GCA?
- Could you spare some time each month to take a few phone calls?

THEN OUR HELPLINE NEEDS YOU!

- Calls are diverted to your home.
- Training and support are provided.
- Maximum of four days needed per month.

We are a really friendly team to work with.

Please email **fiona@pmrgca.org.uk** for a no-obligation chat.

MAKE A DIFFERENCE

REMEMBER A CHARITY IN YOUR WILL WEEK

08-14 September 2025

Remember a Charity Week takes place this year from 8th to 14th September. It's a reminder that leaving a gift in your will can make a big impact to the causes you care about.

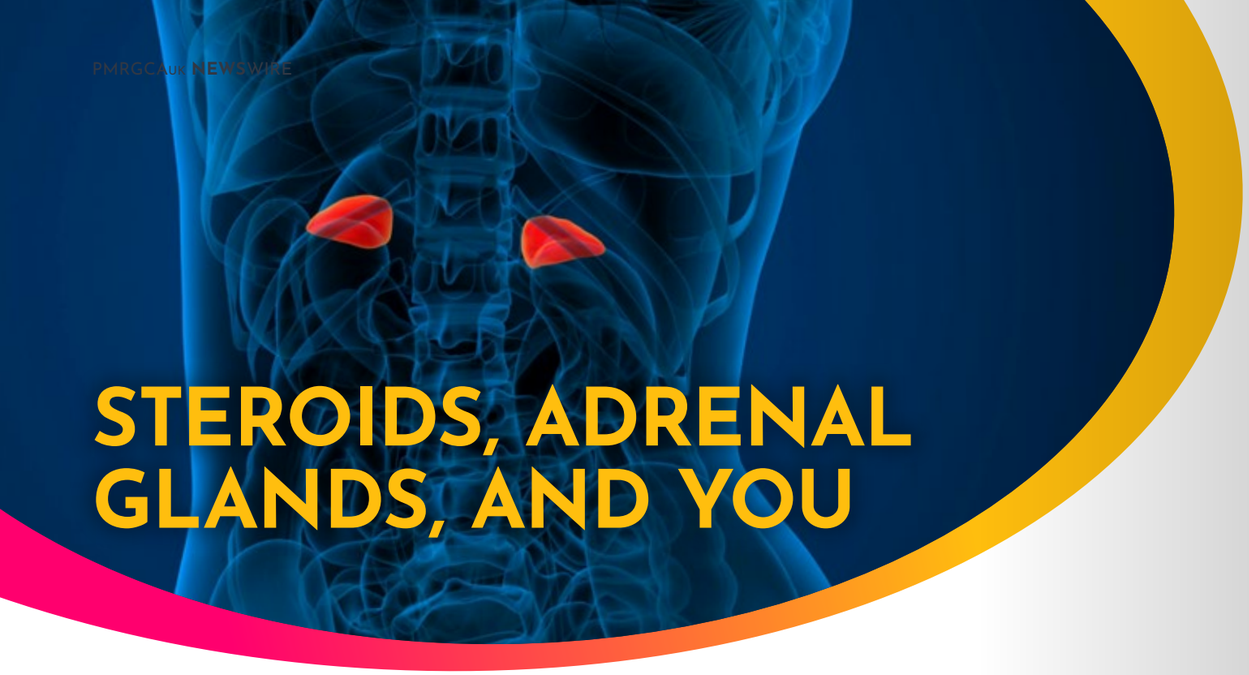
Gifts in wills – large or small – are really important to us. The charity was started with the help of a gift, and we have been able to continue to support thousands of patients with PMR or GCA due to more gifts.

One donor recently told us, "When making our Wills, my partner and I decided to remember several charities that we have supported in our lifetime, so why not when we die?"

If you'd like to find out more about leaving a gift in your will, see our website **https://pmrgca.org.uk/get-involved/leave-a-legacy/** or call the office and ask to speak to Fran or Janette.

"It was easy to decide to choose PMRGCAuk. It is a small charity in need of funds and deserves the support to continue its work into the future."

"I discovered the charity shortly after diagnosis and being a member and a volunteer has been invaluable in helping me to manage my health. I have learnt so much from the HealthUnlocked Forum, webinars and local support group meetings. I hope I have also been able to give support to others, which can continue in a different way by leaving a gift in my Will."



STEROIDS, ADRENAL GLANDS, AND YOU

Probably the most common questions raised by people dealing with PMR/GCA relate to steroids and tapering. We asked Dr Vanessa Quick to explain what happens when you take them and importantly, what might be happening when you reduce your dose.

If you have PMR or GCA, you've probably been prescribed steroids such as prednisolone to control inflammation and ease symptoms. These steroids are very effective, but they also affect how your body works.

Your adrenal glands (small glands above your kidneys) make a hormone called cortisol. Cortisol is really important. It helps your body deal with stress, fight infections, keep your blood pressure normal, and balance energy levels. Your brain keeps your cortisol levels in check by sending signals to your adrenal glands to make more or less, depending on what your body needs.

Glucocorticoids (steroids) are man-made versions of cortisol. If you take them as medicine (especially in high doses or for a long time as is the case with PMR/GCA), your brain tells the adrenal glands to switch off (or "go to sleep") and stop making their own cortisol. Doctors call this "glucocorticoid-induced adrenal insufficiency" or "adrenal suppression" for short. The longer they sleep, the longer it may take for them to wake up.

Therefore, it's very important that you don't stop taking steroids suddenly, and your doctor will usually reduce (taper) the dose slowly to give your adrenal glands time to wake up and start working.

If you become unwell (fever, surgery, infection), your body may need more steroid than usual, this is called steroid cover, a stress dose, or "sick day rules".

Always tell healthcare staff that you're taking or have recently taken steroids, so they will know that your adrenals are likely to be underperforming. Carry a steroid card (available from pharmacies, your GP, or online at **https://pmrgca.org.uk/steroid-emergency-card/**) and consider wearing a medical alert bracelet.

Once you are down to 10mg daily, unless there are specific circumstances that your doctor will explain, the fastest you should drop the dose is 1mg per month. This rate will reduce the risk of your PMR/GCA flaring and minimise the risk of adrenal suppression symptoms occurring.

When you get to below about 4-6mg prednisolone (which is roughly equivalent to the amount of day-to-day cortisol the body normally produces), it's really important to taper the dose slowly, to allow the adrenal glands time to wake up. Dropping too quickly at this point could leave your body short of the steroid it needs.

You should also take all your prednisolone in one go in the morning, to mimic the natural daily peak in cortisol on waking, as that's less likely to cause adrenal suppression than evening dosing or twice daily dosing.

Everyone is different, and some people's adrenal glands take longer to wake up, so they need to taper even more slowly, especially below about 5mg daily. Needing to taper by 0.5mg per month once you are down to these lower doses is not uncommon, especially if you have been on steroids over a year.

The key symptoms of adrenal suppression include fatigue, feeling drained, muscle weakness, low mood, irritability or depression, poor appetite or weight loss, nausea, sleep disturbance, joint and muscle aches, light-headedness or dizziness, and low blood pressure. Inflammatory markers such as CRP and/or ESR blood tests are normal. These symptoms happen because of cortisol deficiency (without enough prednisolone to compensate), not because your PMR or GCA is flaring, although you may have noticed that they can look very similar.

Typically, a flare of PMR comes with a rise in the CRP and/or ESR, plus return of stiffness and pain, particularly in the shoulders or hips, that is worse when you wake up. About half of GCA flares include PMR-like symptoms, even if you've not had PMR before. However, unhelpfully, CRP and ESR can be normal in some flares, and differentiating the two can be quite tricky.

The timing of the symptoms can also be useful. If they happen the day after you drop your dose, then slowly lift over the next week or two, then that's likely to be adrenal suppression rather than PMR/GCA flare.

Regardless of the dose you're on, it's not uncommon to get "steroid withdrawal syndrome" after dropping to a lower dose. This isn't happening because the body is short of cortisol, but because the body has adapted to having the higher dose of steroid on board and needs time to adjust. There are quite a lot of different reasons for this, but one key factor is that long-term steroid use desensitises glucocorticoid (steroid) receptors throughout the body, and it takes them a few days to adapt. A good analogy is being outside when it's very sunny, then going into a dark room, and you can't see anything. There is nothing wrong with your eyes; they have just adapted to the bright light outside and need a few minutes to adjust to the darkness. Steroid receptors seem to take a few days to adjust in some people.

Another reason is that long-term steroids influence neurotransmitter pathways in the brain, including dopamine, serotonin, and noradrenaline. When steroids are reduced, neurotransmitter balance is disrupted, which might affect your mood, energy, and motivation. An analogy might be that if you've been drinking strong coffee every day and suddenly stop, you'll feel sluggish and irritable, not because your body is broken, but because it's adapted to caffeine.

Another reason may be that natural cortisol levels normally fluctuate within the day, and in response to the things that life throws at you. A flat level of daily steroid taken as tablets, when your adrenal glands are sleeping, even if it's above what the body really needs to survive day-to-day, may give you the feeling that your body "doesn't have effective gears".

Adrenal insufficiency and steroid withdrawal syndrome share very similar symptoms, but they are completely different things that often overlap until the body's natural hormone regulation finally recovers after coming off steroids. In some people, this recovery can continue some time after steroids are stopped. In a few people, the adrenal glands never wake up, and long-term steroid is needed.

If you think you might be experiencing symptoms of adrenal insufficiency or steroid withdrawal syndrome, then you should discuss them with your doctor, who may adjust the size and frequency of each steroid drop in your steroid taper. However, tapering in GCA and PMR needs to be individualised to you, your GCA or PMR, the other health problems you have, the other steroid side effects you have developed, and whether you are on any other medications to control your PMR or GCA.

It is also worth planning a quieter few days after each drop in dose to give your body a chance to adapt.

MEMBER'S STORY:

A LONG JOURNEY WITH PMR AND GCA

Warren (82) from North Wales shares his story

In 2010, after many years of window cleaning, I was having difficulty raising my arms past shoulder level. I went to see my GP who said very little about what was wrong but gave me an injection in my shoulder and said that should last me about a year.

I was clear of any pain until 2015. By now, aged 73, I had retired from window cleaning and was managing a block of flats. This time my GP, after viewing the results of a blood test, diagnosed PMR and prescribed 15mg of prednisolone to be taken daily.

As with the injection in 2010, I had immediate relief from the pain which was mainly in my shoulders. My GP said to taper the steroids at my own pace, and over 10 months, I reduced to 5mg, but then the pain returned in my shoulders. My GP advised me to increase my dose to 10mg and then I slowly tapered down to 2mg, which I stayed at for a number of years.

In 2017 I moved to Wales. Wanting to keep active, I joined a badminton club continuing with 2mg daily. In 2021 my GP suggested stopping the prednisolone. Within about a month I stopped taking the steroids with no problems.

However, in September 2023 I was bedridden with back pain. I was given various reasons for the pain: e.g. my age (81 years) and rheumatism. I had various blood tests. In hindsight, the markers for PMR were high but no doctor commented on this, and I wasn't recommended steroids. The pain spread from my back to my hips and down my legs making it very hard to move. I was staying at home, having my shopping delivered to my door. This lasted about a year.

In September 2024 I had terrible pain in my temporal area. It was so intense I couldn't even touch my hair on that side of my head.

My GP was very concerned and ordered a blood test. Upon the results, he recommended a very high dose (50mg) of prednisolone. He diagnosed me with the return of PMR and the pain in my head as the onset of GCA. Within five days the pain in my temple was gone and now, spring 2025, I have tapered down to 6mg. The high dose of steroids in the early days had its side effects, including weight gain and sleep issues, but I was happy to put up with them because of the risk of sight loss.

I am gradually getting back to normal although I have shortness of breath and weak muscles. I am with the respiratory department now and after x-rays, CT scans and lung function tests it appears I have lost about 20% of my lung capacity although it's unclear why this is. My GP and the respiratory department have encouraged me to do more exercise, and I am back cycling and managing 4-6,000 steps a day. I also help an elderly couple with jobs around their home. Motivation is hard to come by, but I keep trying.

I enjoy reading this magazine and reading about other peoples' experience with this painful disease.

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.

A Rheumatologist Explains...

Why aren't DMARDS* used more frequently and at an earlier stage in a patient's journey?

Dr Sarah Mackie
Consultant Rheumatologist

*** Disease-Modifying Anti-Rheumatic Drugs**

David asked: "DMARDs (in my case leflunomide) are used to help patients to reduce and finally stop steroid dependency. Why is it not common practice to introduce DMARDs at an earlier date to avoid long term steroid use? I can see that this would not be possible in the very early stages of treatment as DMARDs are slow working."

This question doesn't have easy answers, but here's my best attempt. Prednisolone is "as cheap as chips" and comparatively easy to start (albeit hard to stop). Long-term, low-dose prednisolone used to be thought of as "replacing" the cortisol the body would naturally make for itself. By contrast, the way DMARDs are portrayed can be quite scary! In reality, DMARDs are very safe when taken as prescribed, and there are good guidelines for clinicians on how to monitor them. It's interesting that steroids are so often prescribed with comparatively little information given about their risks, including rapid-onset side-effects like mood, sleep and hunger as well as the longer-term risks.

Many clinicians think that not every patient with PMR/GCA will need a DMARD. Indeed, some patients seem to taper and stop steroids without any trouble at all; others come to depend on steroids for many years to keep their symptoms at bay. Our problem is that it's very hard to tell at the outset which patients will be able to stop steroids easily, and which patients won't. So, it's argued that we should wait for a relapse before starting a DMARD. But then it becomes tempting to defer the decision, to wait for the next relapse, and the next...

Deferring the decision also feels safer in cases where it has been difficult to confirm the diagnosis of PMR/GCA. It can be necessary to follow a patient up for a good few months to be sure they really do have PMR/GCA and not some other "mimicking" disease. Linked to this is the difficulty many patients now face in seeing the same doctor consistently and when they need to. In a healthcare system under extreme pressure, the "quick fix" of steroids is alluring compared to the slow and careful approach of "doing DMARDs properly", especially because these diseases can be hard to monitor and DMARDs are slow to work.

Society used to be quite ageist and remnants of these attitudes persist in some places. It was only a few decades ago that women retired at 60 and were not thought to be worth very much after that; it was also commonplace for men to die of cardiovascular disease in early middle age. There used to be a view that it was fine to treat "elderly" people with steroids for life, as if they had so little life left to live that it didn't much matter how they lived it. Linked to this was a paternalistic desire to protect "the frail and vulnerable [elderly]", and a fear that adding in too many extra drugs might lead to unpredictable complications. But surely this applies to steroids (and the various drugs routinely prescribed alongside) just as much as to DMARDs. Access to treatment should be based on clinical factors, not age cut-offs.

In summary, in our current world where it's hard to predict who will relapse and who won't, perhaps what it boils down to is this. Should we normalise the practice of offering all PMR/GCA patients a DMARD straight after diagnosis, to make sure that those who will turn out to need it later will derive maximum benefit from these slow-to-work drugs? How do we balance this benefit to the "relapsing" subset of patients, against the downsides (risks and burdens) of DMARD for the "will not relapse" subset of patients? This is a really important question that depends on values ("me" thinking versus "we" thinking). I think there needs to be a public dialogue on this and would welcome the views of those with lived experience. (If you would like to send a message to Dr Sarah Mackie about this, please email **letters@pmrgca.org.uk**)

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.

RESEARCH AND DEVELOPMENTS

Update on the New PMR Treatment Guidelines

Progress is being made on the new British Society for Rheumatology (BSR) guidelines for treating polymyalgia rheumatica (PMR). Dr Task Toyoda, a researcher and doctor from the University of Leeds, has been appointed as the lead fellow working on this important project.

Dr Max Yates, one of the co-leads, said, "So far, we have reviewed and collected all the available evidence from both clinical trials and real-world studies on how PMR is treated. In the coming months, our expert group will meet to start developing clear, evidence-based recommendations and overall guidance for all healthcare professionals in the UK who care for people living with PMR. This includes but not limited to GPs, rheumatologists, geriatricians, specialist nurses, allied health professionals, doctors in training, pharmacists, and also people with PMR and other stakeholders. These new guidelines will help ensure that everyone with PMR receives the best possible care, based on the latest research and expert advice."

The group is aiming to share the guidelines at the BSR Annual Conference in 2026.

Trustee Janice Maddock who is a patient representative on the BSR Guideline Working Group said, "I have been talking about my experiences of living with PMR including issues and barriers that I faced along the way. The group is very keen to ensure that the work they are producing is totally relevant to people with PMR. It means a lot to me personally, and I welcome the fact that the outcome will be guidelines that I would have loved to have seen when I was diagnosed. It is great to be able to feed into a process that would mean that patients should have the best advice and care through this debilitating condition."

PMRGCAuk Exercise booklet goes International

Since the UK launch in January 24, the Maintaining Movement, Activity and Exercise in PMR booklet, written by Dr Anne O'Brien with patient input and funded by a charity member donation, has expanded its reach. Rheumatology networks in Australia, Tasmania and the United States have shared the resource via their websites and health professionals. 98% of those who have evaluated it say they would recommend it to others!

You can request or download a copy on our website **https://pmrgca.org.uk/information-and-advice/resources/**

Dr O'Brien requests that people continue to give their feedback, and we request a donation towards p&p if possible.

SAPHYR research article published

A research article led by Prof. Dasgupta and Prof Strand (from Stanford) analysing data from the SAPHYR trial has recently been published (June) in the Lancet Rheumatology. The article, on patient-reported outcomes in relapsing PMR, analysed the quality of life (QOL) in patients recruited to the SAPHYR trial of sarilumab in relapsing PMR.

In lay terms, it found that QOL is much lower in people with PMR as compared to normative controls as measured by several instruments (including SF-36, EQ5D). QOL improved significantly with sarilumab compared to those on glucocorticoid therapy only. The largest improvement in QOL was seen in patients with most severe disease.

Prof. Dasgupta said, "The implications for PMR guidelines are that PMR should be stratified - sub grouped according to severity of disease and those with severe disease offered additional therapy options either DMARDS or the emerging biologics and not just steroids alone. These patients should be looked after in secondary care. Activity of PMR assessment should include patient reported outcomes such as disability and quality of life."

The main trial report from SAPHYR was published in the New England Journal of Medicine. A summary of the Lancet article can be found here

https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913(25)00041-4/abstract

GCA-PMR spectrum research

Prof. Dasgupta and the researchers involved with the GCA-PMR spectrum study have completed the Delphi survey (a research method) after two rounds. They are now analysing the results. However, preliminary analysis appears to show strong consensus for the spectrum concept, now called GCA PMR Spectrum Disease (GPSD); the individual phenotypes within GPSD; a need for imaging to identify these phenotypes and exclude alternative diagnoses; and a need for stratification i.e. allocation to disease sub-groups according to prognostic risk based on clinical, imaging, laboratory biomarkers and patient specific factors to choose the optimal therapeutic approach for individual sub-groups.

Prof. Dasgupta thanked all patients and clinicians who took part in this survey.

Sterling Study begins recruitment

A clinical trial called STERLING-PMR, which is led by the University of Leeds, is currently recruiting from hospitals in the UK and Australia. Dr Sarah Mackie, Chief Investigator of the trial, and the researchers want to find out whether adding "disease modifying anti-rheumatic drugs" (DMARDs) to steroid treatment helps people with relapsing polymyalgia rheumatica (PMR) to reduce and stop their steroids. The DMARDs they are testing are methotrexate (MTX) and leflunomide (LEF). Even though MTX is recommended in guidelines, only 6% of NHS patients with PMR take MTX and part of the reason is that MTX has only been tested in new-onset PMR, not patients with PMR who have tapered prednisolone and then relapsed. They are aiming to recruit 200 participants in total and so far have recruited just over one-third of this number. People with PMR that have relapsed at least once can self-refer to the study - more details at **https://ctru.leeds.ac.uk/sterling-pmr-uk/**.

PMRGCAuk Webinars

Thank you to the clinicians, Dr Mark Hughes, Prof. Toby Helliwell and Prof. Susan Mollan who gave such interesting talks across June for PMRGCAuk Week. See over the page for Dr Hughes exercise webinar report. The other two webinars were too late for a report in NewsWire but all recordings are available on our website:

https://pmrgca.org.uk/pmrgcauk-week-webinars/

The webinars were fantastic. If you are able to, we urge you to watch them.

"I have learnt so much in such a short time."

WEBINAR ATTENDEE

Marathon in a Month 2025

Webinar: Exercise with PMR/GCA

To help launch our summer walking campaign, Dr Mark Hughes, Rheumatology Consultant Royal Cornwall Trust with a diploma in sport medicine, spoke about the benefits of exercise in managing PMR and GCA.

PMR physiology and steroids

Dr Hughes summarised the typical symptoms associated with PMR, noting inflammation and reduced mobility. Steroids treat the symptoms very well but often come with side effects including weight gain, osteoporosis (weakened bones), sarcopenia (loss of muscle mass and strength) and mood disturbance.

Exercise can help tackle some of the symptoms of PMR and also some of the side effects of the steroids.

PMR is driven by a chemical called IL-6. Research into IL-6 found there is a short-term increase following exercise, which can lead to delayed onset muscle soreness (DOMS). DOMS can mimic PMR symptoms and make people think they are having a flare. However, regular exercise is linked to lower levels of IL-6 over time, and increased levels of anti-inflammatory cytokines.

Barriers to exercise

Doctors don't always promote exercise to PMR patients, especially when someone is in significant pain with the condition. Lack of time, motivation, being unsure what exercise to do, and the individual symptoms of pain, fatigue and stiffness can all be barriers to exercise.

Facilitators to exercise

Advice and encouragement from healthcare providers, social support – friends and family exercising with you, and the benefits of reducing stiffness are all things that can encourage people to exercise more.

Benefits of exercise

Regular exercise has many benefits including long-term reduction in pain, increase in serotonin and endorphin levels, reduced fatigue (after 12 weeks), increased bone density, weight loss, reduced cardiovascular risk, improved blood sugar levels and blood pressure, and reduced atherosclerosis (arterial plaque). Clinical studies show exercise increases shoulder mobility, reduced duration of morning stiffness and greater success tapering steroids for those with PMR.

Types of exercise

Different exercises are classed as aerobic, which increases your cardiovascular health; strength, which improves mobility and daily function; and balance, which reduces your risk of falls. Exercises are not mutually exclusive to these categories and can overlap. You can use a speech test to measure the level of aerobic exercise that you are doing:

Can sing – light intensity – increase activity.

Can just speak a full sentence – moderate intensity.

Can grunt a few words – intense activity.

Can barely speak – too intense.

Getting started and keeping motivation

Keep an activity log, set realistic goals, join community classes, use social support.

To catch the Q&A that followed Dr Hughes' talk, we would encourage you to watch a recording of the talk which is available at **https://pmrgca.org.uk/pmrgcauk-week-webinars/**.

Fundraising

At the point that NewsWire is written, participants' walks hadn't yet begun but we were really excited to hear about people's plans and to see that the fundraising had begun: £2,000 in June! Thank you to everyone who got started early and for their sponsors.

One member was planning on walking two marathons during July. The support groups taking part were arranging to kick off their group walks in scenic locations including RHS gardens and country parks. Some were walking with friends and family, and one member with friends from her line dancing group!

Thank you to Adrian Gilbert, a member in New Zealand, who didn't feel able to complete a walking marathon but made a donation based on the miles he had swum in the Ngunguru Estuary during his swimming season which finished just as Marathon in a Month began. He swam over a mile a day, totalling 181 miles! Adrian, a retired pilot, also took the image below of the estuary where he swims.

It is still possible to donate on the charity campaign page **https://www.justgiving.com/campaign/marathoninamonthforpmrgcauk**

Please send in any collected cash or cheques, along with any sponsor forms, or transfer to our bank account. Please email **charon@pmrgca.org.uk** if you need our bank details.

Helpline
0300 777 5090
www.pmrgcascotland.com
Registered Scottish Charity No: SC051207
Tigh na Fraoch, Nethy Bridge, PH25 3DA

Pmr Gca SCOTLAND

Notes from the Chair – Richard Cuthbert

June 2025

It was AGM time again in May and we had a good turnout of members scattered all round the country and even further afield. There is great pleasure in welcoming people who would not be able to attend an in-person event, but also a trade-off with the loss of personal contact and informal conversation. It is quite difficult to twist arms for volunteers down a fibre optic cable! The main aim though is interaction with members, and our speaker was a great success in engaging with the gathering. Dr Lisa Hutton is a consultant rheumatologist at Inverclyde Royal Hospital and has developed an interest in the different forms of vasculitis. Often our charity work is centred on GCA which is understandable in view of the serious potential outcomes, but Lisa wanted to talk about PMR which is more relevant to the majority of our members.

Lisa took us through a typical PMR journey, starting with symptoms, diagnosis, confirmation techniques, and then treatment. She explained how the doctors approach each stage and touched on the alternatives that had to be considered and decided on at every point.

I was delighted to hear how Lisa welcomed input and questions from her patients – she clearly believes that a patient is better off knowing the hows and whys of the treatment regime. Each appointment letter calling in her patients contains a BRAN questionnaire[1] which encourages patients to ask questions along the lines of:

B – what are the Benefits of this test or procedure?

R – what are the Risks of this test or procedure?

A – are there any Alternatives?

N – what if I do Nothing?

This simple resource comes from NHS Inform and has been adopted by NHS Greater Glasgow and Clyde, but I have never seen it in letters from my own health board. I can't help feeling that every health board should be using it as much as possible to encourage patient involvement. The resource also suggests that the clinician asks the same questions of themselves about what they propose to do, with the nice twist that the N question becomes "If I were this patient, would I consider doing nothing at this stage?".

Another interesting point was hearing that PMR is unusual as a rheumatological condition in that it is mainly treated with steroids alone – most other conditions use more modern drugs, either alone or to supplement the steroids. Ongoing research work may lead to breakthroughs in drug options, but we often come back to the excellent cost/benefit ratio of prednisolone.

The business side of our meeting went smoothly, and I was delighted that a couple of members put their names forward as being willing to help with aspects of our activities. Volunteers will be welcomed at any time!

Since last writing, our charity was pleased to supply volunteers to give patient feedback on their GCA experiences. This was to assist a researcher preparing a project proposal to do detailed work on the blood cells that damage tissue and keep inflammation going. In the future, intervention targeted at these cells might be able to reduce chronic inflammation, reduce the steroid burden and improve remission. Such an outcome could have benefits for a range of other conditions which involve inflammation – not just PMR and GCA.

I am finishing this piece before heading off on holiday. If you are preparing for a holiday, be sure to pack plenty of your medications. Any unexpected delays can cause enough stress without adding in a medical emergency due to running out of tablets.

1 **https://rightdecisions.scot.nhs.uk/realistic-medicine-national-toolkit-for-professionals/quick-access-to-patient-care-resources/bran-helping-patients-ask-the-right-questions/**

Our network of groups around the country is growing!

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