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NEWSWIRE

SPRING 2022
ISSUE 36

RESEARCH SPECIAL EDITION

PMR RESEARCH GRANT

PMR VOICES PROJECT

UK AND DANISH FAST-TRACK STUDIES

FIND OUT ABOUT TARGET

SARA MULLER'S RESEARCH ROUND-UP

+ See what's on this PMRGCAuk Week

MEMBERS ASK THE RHEUMATOLOGIST: HOW LONG SHOULD PMR LAST?

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Welcome

I'm delighted to be welcoming you to this spring edition where we have a particular focus on research. There is so much still to understand about auto-immune diseases in general, and PMR and GCA specifically, so it is always heartening to hear about scientists and doctors in the UK, and further afield, who are striving to learn more about these conditions and how to treat them.

I hope you enjoy reading about the research and studies that have taken place or are ongoing, and our own research grant that has now been awarded and began in March. It will focus on understanding and improving the implementation of current guidelines for treatment of PMR. We also report on the PMR Voices project led by Dr Sarah Mackie at Leeds University Hospital, who along with her team, is looking at how the lives of people with PMR could be improved. Some of you may have taken part in her survey or workshops earlier this year and will be particularly interested to hear what the outcomes are so far.

Sara Muller brings her thoughts to three pieces of PMR research and we also showcase some studies which demonstrate how well-structured pathways can improve diagnosis for either condition, which in turn results in more positive outcomes for patients. And finally, for those of you not aware of the TARGET consortium, we introduce this partnership between some of the leading universities and hospitals who are focused on improving the outcomes for people with GCA.

Notwithstanding all those articles, we also have our regular information about support groups, an interesting Your story about atypical GCA, news of PMRGCAuk Week in June and Dr Sarah Mackie's popular column which deals with a question we hear all too often – is it normal to still have PMR after two, five or even ten years? I'll leave you to read what Sarah has to say about that.

Humphrey Hodgson

Humphrey Hodgson
Chair of Trustees

SAVE THE DATE
PMRGCAuk Week
runs from 6th – 13th June 2022

6-13 JUNE

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 health care provider regarding your own medical condition or treatment. Never delay in seeking medical treatment because of something you may have read in this magazine.

RESEARCH ROUND UP

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

RESEARCH SPECIAL EDITION

For this edition, I've picked out three small studies on PMR that I thought you might find interesting.

The first study, from Japan, looked at 34 people with PMR and 37 with rheumatoid arthritis[1]. It showed that the proportion with adrenal insufficiency (this is where the adrenal gland isn't working properly) is much higher in people with PMR (76.5%) than in people with rheumatoid arthritis (35.1%). After allowing for differences in age, sex and steroid dose, people with PMR were nearly seven times more likely to have problems with their adrenal function than people with rheumatoid arthritis. The authors think this is related to the use of steroids (which are also used to treat rheumatoid arthritis). They say this calls for a more appropriate strategy to reduce steroid use in people with PMR.

Related to this, another study in Japan has looked at the ease with which people with PMR stop taking steroids[2]. They found that 52.5% of people were still taking steroids seven and a half years after their diagnosis and that this was higher in women (69.2%) than in men (21.1%). They looked at other factors that might be associated with difficulty stopping steroids and found that being anaemic and having a relapse were associated with still using steroids. Age, a range of blood tests and steroid doses were not related to continued treatment.

Finally, a study from Denmark[3] has shown a substantial reduction in the rate of hospitalisations linked to a PMR diagnosis after the introduction of a fast-track clinic for people with suspected PMR (from 20.4% to 3.5%). They also showed that there was a decrease from an average of four days per inpatient stay to one day. Whilst it is very uncommon to be hospitalised with PMR in the UK (I don't think we have data, but it is rarely discussed), this marked reduction in Denmark raises questions about the potential use of such fast-track pathways here.

None of these studies are especially high quality, or possibly all that surprising, but they do highlight again that PMR is not as straightforward as it is often described. I'm sure you know that already.

1 Risk of Adrenal Insufficiency in Patients with Polymyalgia Rheumatica Versus Patients with Rheumatoid Arthritis: A Cross-Sectional Study - PubMed (nih.gov)

2 Withdrawal of Glucocorticoid Therapy is Difficult in Women with Polymyalgia Rheumatica: An Observational Study - PubMed (nih.gov)

3 The fast-track outpatient clinic significantly decreases hospitalisation rates among polymyalgia rheumatica patients - PubMed (nih.gov)

CHARITY NEWS

PMRGCAuk research grant is awarded

RESEARCH SPECIAL EDITION

We were very pleased to award our research grant to Dr Max Yates, Clinical Associate Professor at Norwich Medical School. Dr Yates' proposal will help patients with PMR by better understanding the extent to which guidelines for PMR are implemented and adhered to nationally, to identify the reasons why there is variation in steroid use and put in place strategies to optimise care.

For the majority, steroids are an effective treatment and uncomplicated disease can be managed in primary care with the support of established national guidelines. Currently it is recommended that patients newly diagnosed with PMR are started on higher steroid doses, and when the condition is brought under control, the dose is slowly reduced and eventually stopped. Despite these guidelines, there is wide variation in steroid prescribing for PMR. The guidelines also recommend that individuals with PMR who need to be on steroids for longer than two years are referred to a rheumatologist. However, over half of patients with PMR are on steroids for longer than this and yet up to 84% are managed by their GP alone.

There are also big differences across the UK for rates of steroid prescription which suggests care for many with PMR is not optimal, with some patients exposed to unnecessary long-term exposure to steroids, which increases the risk of osteoporosis and broken bones, diabetes, heart disease and cataracts. The variation also suggests that many people might be missing the opportunity for being offered other treatments through referral to secondary care.

The study will look at the electronic general practice records of 23 million patients held in a database which includes detailed patient information including diagnoses, medication, diagnostic test results and anonymised details such as age, sex, and practice location. This information will be used to look at the prescribing patterns for patients with PMR and look at what characteristics are associated with the different patterns and how they might be mitigated.

As this is a live system, these insights will be used to develop a desktop-based alert system to standardise care and improve adherence to NICE guidelines, including referral to secondary care when appropriate.

Humphrey Hodgson, Chair of PMRGCAuk, said: "While many people with PMR get good treatment from their GPs, we are all too well aware that this is not always the case. Often, and worryingly, this is because the recommended guidelines for caring for people with PMR are not being followed – and this is particularly true about the dosing and duration of treatment with corticosteroids – prednisolone – which is the backbone of PMR treatment. By investigating just how often treatment falls short of the guidelines, with a huge survey based on National GP prescribing, this research will facilitate moves to improve standards of treatment in the NHS."

Trustee News

Thank you to Dr Chetan Mukhtyar who is stepping down as trustee due to increasing work commitments. We are very grateful for the support that Chetan has given to the charity during his two years on the board. His knowledge of PMR and GCA has been hugely beneficial to the charity and we are pleased that he will continue to support us as much as possible in the future.

Congratulations to trustee, Sara Muller, who was selected as the winner of the Paul Bacon Vasculitis Award for her abstract entitled 'Long-term use of glucocorticoids for polymyalgia rheumatica: follow-up of the PMR Cohort Study'. She is invited to present her work at the annual conference for the British Society of Rheumatology and it will also be published in the journal Rheumatology. In addition, she will be giving a webinar on the subject during PMRGCAuk Week.

PMR VOICES

RESEARCH SPECIAL EDITION

Collaboratively laying the stepping-stones for improving PMR experience

Last year Dr Sarah Mackie received support from the University of Leeds – as part of a Wellcome Trust funded initiative – to listen to what people with PMR had to say about what might make things better for them. The project, titled PMR Voices, was designed and delivered by Sarah, two patient involvement specialists (Amy Rebane, Hanif Ismail) and two patients (Lorna Neill, Margaret Grover).

They started by sending out an anonymous online survey for patients or carers to tell them about one moment – a tiny 'story' from their PMR journey – that had meaning for them (these were called 'meaningful moments'). They also asked them to rate whether the moment was good or bad; and if it involved managing their own PMR (self-management), healthcare services, or other people. Thanks to the global communities that shared the link online – including on the PMRGCAuk forum on HealthUnlocked – they received 299 responses in three weeks!

Sarah said: "What struck us from all the responses was how many of the stories were both about self-management and about health services. These 'both-and' stories were also the ones most often rated as 'good' moments. So, we selected several 'both-and' stories for discussion in a series of online workshops where 29 people shared their personal thoughts and experiences of PMR. Some of the groups were facilitated by Patient Research Champions who did a great job."

This sharing of stories generated many ideas for change and themes started to emerge. In two final online workshops these ideas and themes were discussed with a mixed group: patients, representatives from charities (including PMRGCAuk), healthcare professionals and other stakeholders. Forty-eight people took part in these final two workshops. An artist, Tom Bailey, vividly captured some of the ideas discussed (right).

The biggest theme was the need for education about PMR and its treatment, especially steroids – not just patient education, but also education of healthcare professionals. Other themes that came through strongly included needing to raise public awareness about PMR and the need for a better diagnostic toolkit for PMR.

This project ran during the second winter of COVID-19: a difficult time for many. In summing up, Sarah said: "We deeply appreciate and value all the contributions made. Rather than formal research, we view this as vital patient involvement to inform priorities for future research and clinical service improvements. The challenge now is how we begin to make some of those ideas happen!"

If you would like to find out more or get involved, please contact Amy Rebane on **a.k.rebane@leeds.ac.uk**.

Illustrations by Tom Bailey

Groups around

Bedfordshire Group has been meeting at Frosts, Willington, on the last Thursday in the month since November. There are ten members and one has been off prednisolone for a year and another is now down to 0.5mg.

Brighton Group met face-to-face, for the first time since Covid, in February and were also joined on Zoom by those who couldn't make it.

Cambridge Group are yet to set up face-to-face meetings. One of their members died from Covid while in hospital. They are such a small group that this was a great loss. When the group resumes they hope to welcome the two new members who joined just before Covid set in. If you would like more information from them and to hear when meetings are due to resume, please email **cambridge@pmrgca.org.uk**.

Harrow/Pinner Group met in January and discussed the different side effects of steroids and how they manage them. Over 15 different side effects were discussed and ways people try to overcome them including things to avoid – some more successful than others. They also discussed the possibility of starting a new group in nearby Ruislip.

Can you help?

Harrow/Pinner group is temporarily being run by Janice Maddock after the previous group organiser had to step down. We are looking for a new group organiser for this group. If you think you could help and would like to find out more, please contact **candy@pmrgca.org.uk**.

Orpington Group enjoyed watching a recording of Professor Justin Mason's talk from the 2021 Members' Day. The group members have appreciated being able to meet up to share their news and have been arranging to meet each other outside of the group for coffee or exercise.

Oxted Group – who have been meeting for approximately seven years – have found a permanent home for their meetings in the local cinema which works very well: good coffee, comfy chairs and so far, quiet for everyone to hear.

Trent Valley held a Zoom meeting in January and welcomed a new member. They were planning a face-to-face meeting at the end of March.

Truro Group held an enjoyable Christmas Lunch at Truro Golf Club in December. Unfortunately, the group organiser broke her ankle in February and so the monthly meetings were put on hold for a while. They were hoping to start meeting again in March.

Welwyn Garden City Group continue to meet online via Zoom as many members have co-morbidities and continue to feel vulnerable or do not wish to travel to meetings.

Whitstable Group had a great Christmas lunch in December. In February they watched Professor Justin Mason's talk (recorded from our AGM) and heard from an NHS Physio in March.

Worthing Group meet every six to eight weeks and currently have 13 members, four of whom have joined in the past few months. They met in a local café in December, but in January decided to avoid busy restaurants and instead met via Zoom. However, most of their members prefer to meet face-to-face so they are planning to meet face-to-face from March.

In January, **Yorkshire Group** hosted Dr Sarah Mackie who gave a talk on PMR diagnosis and treatment, and her recent research, PMR Voices, that some of the Yorkshire group members had contributed to. Approximately 26 people joined the session including volunteers from the PMRGCAuk helpline and staff from head office.

The **WedPM Zoom Group** (an online group run by trustee and Orpington group organiser, Penny Denby) meets monthly. The meeting topics follow a similar pattern to Orpington Support Group's programme. In February they had a lively discussion after watching Professor Mason's talk, and the dead slow/nearly stop steroid tapering method was circulated.

Dartford Group had a Lions speaker for their March meeting and are planning Art Therapy for April, a tour and fundraiser at Coolings Garden Centre at 11am on Wed 4th May and informal coffee and catch up in June. Please contact Suzanne on **dartford@pmrgca.org.uk** if you would like to join for any of these events.

The first meeting of the **Sevenoaks, Tonbridge and Tunbridge Wells Group** welcomed six members at the White Hart pub in Sevenoaks in January. They enjoyed a good chat with lots of ideas for future meetings. They haven't yet decided on a regular meeting day and time and are also currently alternating venues to accommodate the wide area from which members are coming. Please contact Neelam on **kentro@pmrgca.org.uk** for further details.

the country

Southend/Chelmsford Group held a special meeting in February to remember the advances that have been made in patient services for people with PMR/GCA; to recognise the work that Professor Dasgupta has done in Southend and beyond, and to also celebrate that Southend/Chelmsford group has been running for 15 years.

Eminent rheumatologists from around the world who had worked or studied with the professor submitted presentations to be shown at the meeting. Live talks were given by the professor, Madeline Whitlock, and Alwin Sebastian (who recently did his scholarship at Southend and now works in Limerick).

In attendance were Hannah Padbury, who founded the Southend group, 48 group members along with the Chelmsford Mayor, Cllr. Jude Deakin and the Deputy Mayor, Cllr. Linda Mascot. Many others were also able to join via Zoom. This included representatives from PMRGCAuk, group organisers, Southend/Chelmsford group members who could not attend the meeting in person and many of the doctors who had made presentations: from the Mayo Clinic USA , Mumbai, Bangalore, Netherlands, Milan, University Hospitals in Warwickshire and Anglia Ruskin University, Chelmsford.

Special thanks to group member, Chris Poole, who prepared all the presentations, MC'd the meeting and ran the Zoom.

L–R Madeline Whitlock, Hannah Padbury, Professor Dasgupta, Pat Fedi, Chris Poole and Gill Poole.

L–R Dalia Dasgupta, Professor Dasgupta, Pat Fedi, Chelmsford Mayor Councillor Jude Deakin, Chelmsford Deputy Mayor Councillor Linda Mascot, Alwin Sebastian, Madeline Whitlock and Hannah Padbury.)

New Group

A new support group in Oxford, led by Dr Shirish Dubey, Consultant Rheumatologist at Nuffield Orthopaedic Centre in Headington, is due to start in early summer. Please contact **candy@pmrgca.org.uk** for more details.

Spotlight on Group Organisers

Group Organiser: Lorna Neill
Group Name: Dundee Support Group

Condition: I have had a refractory form of PMR for the last 12 years and am now maintained on 5mg prednisolone and 20mg leflunomide with no symptoms of PMR.

How many people typically attend meetings? The group has about 40–50 occasional attendees, although any given meeting usually has between 10 and 20. We managed a face-to-face in November 2021 which had 17.

How often do you meet? A Dundee group has met monthly now for fifteen years, initially as Tayside PMR and GCA Support, then from 2010 this expanded to become the charity PMRGCA Scotland.

What is the format of the meetings? We welcome any new members, listen to their stories if they wish to tell them and answer any questions if we can from our own experiences. It's amazing how this can often take up a whole meeting when coffee/tea and biscuits are added in! Any new information from the charity is passed on and there is usually a planned topic for discussion which I keep in reserve if nothing arises naturally. Occasionally we have a speaker. These have included a Tai Chi instructor, an occupational therapist and a pharmacist, along with others from nearby local support groups for those with long term conditions. Members of our Local Health Council have talked about opportunities for patient involvement and researchers have described what they are doing and used members as a patient forum or to complete a questionnaire.

How has coronavirus changed that? We meet in a city centre church which has been closed to outside organisations for most of the time. Just after we thought things were back to normal at the end of last year, restrictions unfortunately returned after only one meeting. In the meantime, members have been using the Helpline if needing to chat or they email me for specific information, while many of the group see each other on PMRGCA Scotland's monthly Zoom meetings. I hope that we'll be back to normality soon.

Why did you decide to set up/take over a group? Jean Miller, the founder of both the group and Scottish charity, was wanting to retire. I had benefitted so much from the knowledge and support I had received as a group member that I was happy to take over so that others could enjoy the same.

How much time does it take? Paperwork such as maintaining membership lists and preparing an agenda and record of monthly meetings plus liaising with our venue as required takes about half a day a month. In the days when speakers were being organised to talk to our group and we provided speakers and publicity for the charity at meetings of other organisations in the Tayside area this could increase to a couple of days a month.

Does anyone else help you? Yes, very much so. Almost everyone helps on the day, setting out chairs and tables and the book display. We have long-term members, Margaret and Christine, who magic up the coffee, tea and biscuits. They and others have accompanied me to speak at events and all group members help with suggesting speakers. More than that, is that the group is its members; it is their company and their willingness to share experiences that we all lean on when we need support.

If you'd like to join the Dundee Support Group, please email dundee@pmrgcascotland.com

If you'd like to set up a group in your area or find out how you can help an existing one, please email groups@pmrgca.org.uk

FUNDRAISING

PMRGCAuk Week 6th – 13th June

We are very much looking forward to PMRGCAuk week this summer and hope that now Covid restrictions have been lifted that many of you will be able to organise and take part in a coffee morning or afternoon tea. Some of you may wish to plan one with your support group while others may see it as an opportunity to meet up with other friends and fundraise.

Alternatively you could organise a sponsored walk or run or a quiz! Do get in touch for more information or support with any fundraising. You can set up a Just Giving page for people to contribute or sponsor you at: **https://www.justgiving.com/pmrgcauk**

WEBINARS: We will be hosting two webinars to which everyone is welcome, so please make a note of these in your diary.

Tuesday 7th June 11am: Talk on Osteoporosis
Sarah Leyland, Specialist Osteoporosis Nurse and Clinical Advisor for the Royal Osteoporosis Society

Friday 10th June 11am: Long-term use of glucocorticoids for polymyalgia rheumatica: follow-up of a PMR Cohort Study
Sara Muller, trustee and Senior Lecturer: Inflammatory Research Programme and Biostatistics Group at Keele University

Plus a webinar on GCA on Wednesday 8th June – details to confirmed. Further information will be emailed out closer to the time.

Legacy for PMRGCAuk

During PMRGCAuk Week why not consider how you might be able to help PMRGCAuk in the future?

The charity was founded with a very generous legacy and we would not have been able to set up the helpline or website without that funding. We have been supporting people with PMR and GCA since 2009 and although a small charity, our impact has been far reaching – helping thousands of people each year through the services we provide.

Gifts in wills are an important part of any charity's income, and such gifts received by PMRGCAuk from generous supporters could help to continue to fund our work for many years into the future. Every year around 45,000 people in the UK are diagnosed with PMR or GCA; they will benefit from the generosity of our supporters, helping us to expand our services, campaign for the best treatment and use of resources for all and reach as many people as possible who need our help. Wills are vital for providing for your family and a wonderful way to remember a cause that has been important to you. Your financial gift can be as small or as large as you wish.

Writing Your Will

Your will is an opportunity for you to continue to help and provide for the people you love. Having an up-to-date will is the only way to make sure that your family and friends, and any charities you care about, are provided for as you intended. Dying 'intestate' (without a will) means the government will decide the order of who gets what from your estate, irrespective of what you might have wished. We would always recommend consulting a solicitor to ensure that all the legal formalities are correctly followed, and your will is valid. For more information you can visit our website at **https://pmrgca.org.uk/how-to-help/leave-a-legacy** or email **info@pmrgca.org.uk**

Photo competition

Our 2022 calendars sold within a few days last year and so once again we are running a photo competition. Hopefully even more of you will be venturing out this summer so remember to take your camera or phone and send in any entries to **cards@pmrgca.org.uk**. Images should be greater than 500kb in file size and by entering you give your consent for your photo and name to be published on the calendar, in NewsWire and on social media.

PMRGCAuk notelets in PMRGCAuk Week

These lovely cards, showcasing two of our favourite members' images from the last two photo competitions, will be available to buy in PMRGCAuk Week.

Details of price and how to buy will be announced closer to the time. Enquiries to **cards@pmrgca.org.uk**.

Squirrel by Jill Jopson

Crocuses by John Minter

Members' corner

A warm welcome to all our new members and thank you to Phil who sent in his story.

YOUR STORY:

DEALING WITH PMR AND LARGE VESSEL VASCULITIS

Phil (61) from West Sussex shares his experience with us.

I was initially diagnosed with PMR by my GP in 2017 when I was 57. I had the classic symptoms of stiff and painful neck and shoulders as well as having difficulty getting out of bed and moving in the mornings. Starting steroids had a dramatically positive effect. Two years later a rheumatologist told me I didn't have PMR and to come off steroids. I did as instructed, but after one month I went back to my GP as I had pain around my hips and walking was so slow and difficult. My C-reactive protein (CRP) blood test was 30 indicating inflammation. I was started on steroids, again with a rapid positive result. I took my work pension early so that I could reduce my work hours as full-time had become too difficult.

Over the next several months the lowest dose of prednisolone I was able to be on was 6mg although this dose was often a little higher as I continued with pain in my neck and shoulders. Then in July 2020 I noticed a marked deterioration in my walking. I was feeling quite exhausted with exercise despite being fit and active, including a lot of hill walking. The change was stark. I saw another rheumatologist who again told me I didn't have PMR and to get off steroids. He did though refer me for an FDG PET-CT scan. From this a diagnosis of LVV was made in September 2020. I had inflammation in my aorta, carotid and sub-clavian arteries. I then started high dose prednisolone (40mg daily) but disappointedly I felt no better and was started on methotrexate as well in October. I found I could not reduce the prednisolone below 20mg without being very fatigued and started tocilizumab injections in February 2021.

I needed five months off work, from my job as a specialist nurse, at the end of 2020. I was constantly fatigued, walking was a great effort, I had palpitations, a pulsating head at night, and tense temples. My level of physical functioning was about 30% of what was normal for me.

I had a phased return to work managing just a few hours daily over a three-month period.

In October 2021 I reduced my working hours further as it was still a struggle physically. Although the tocilizumab has enabled me to reduce my prednisolone dose to 2.5mg daily I still find work exhausting and I am reluctantly having to think of retiring.

The physical challenge with this condition is obvious but the mental challenge has been significant too. I have been very sad acknowledging many losses and been moderately depressed and used an NHS counselling service. I mourn the person who was fit, who did physical tasks without thinking. PMR and then LVV has made me reduce my working hours and will ultimately make me give up work. There have also been financial losses. Socially, I have withdrawn, partly through feeling fatigued and partly due to Covid. It is difficult for other people to understand what I have been going through and it has felt lonely and frightening at times.

I am due to complete my allocated 12 months of tocilizumab treatment very soon and hopefully I will have a further scan and will then know if the treatment has been effective. Currently, my level of physical functioning is about 75%. I have come a long way but hope I will achieve the last 25%. I'm an optimistic person and will continue to work at it and thank my lucky stars for the great support I've had from my wife, and the kindness of family and friends.

Note: Large vessel vasculitis is an atypical presentation of GCA.

IN MEMORY:

Ruth Fisher, a member since 2010 who passed away quickly and without pain in December.

Wendy Maybrey had a heart attack and died in November. She was a supporter of the original Sevenoaks Support Group and later joined Orpington and Oxted Support Group meetings. She will be remembered and missed by members of both groups.

THANK YOU TO:

All our members who have made donations throughout the year:

Julia Marsden for raising awareness of PMR and GCA through publishing her beautiful flower photos (opposite) on Instagram and for her very kind donation.

To members who have kindly donated their Winter Fuel Allowance and also to relatives of members who have made some very generous donations and organised fundraising over recent months.

Judi Saunders, Master of the Portsoken Ward Club – the social hub of the Portsoken ward, one of the twenty-five ancient wards of the city of London. Judi nominated PMRGCAuk as their charity in 2020. After some initial fundraising, activities and efforts were sadly affected by the pandemic. However, they decided to keep us as their charity for another year. More fundraising is planned over the next few months.

VOLUNTEERS WEEK 1-7 JUNE

Thank you to our amazing volunteers who help with support groups, the helpline, the online forum, NewsWire, sending out cards and calendars and the many other jobs that they do.

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

It also helps us to raise awareness and fundraise if people understand the conditions through patients' real experiences. Please contact **fran@pmrgca.org.uk** or call 0300 999 5090 if you can help.

A Rheumatologist Explains...

Dr Sarah Mackie
Consultant Rheumatologist

We received several emails and letters asking if it was normal to have PMR for several years. One member who asked, has had it for more than 12 years, another included a question about the significance of good days – a 'resurgence'. In this edition, Sarah, talks about steroids, relapses and resurgences.

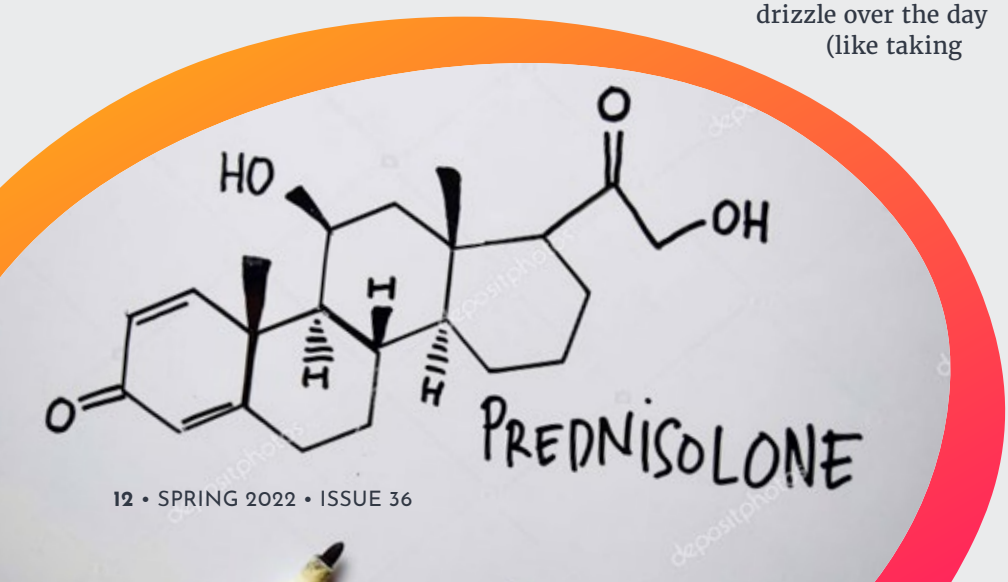
Dear reader,

If you have been taking steroids for PMR for a long time, I need to tell you that this is not your fault and you have not done anything wrong. About one in five people with PMR take steroids for over five years; ten years is not uncommon. PMR is a long-term medical condition, not a "fix and forget" thing. But why does PMR affect different people so differently?

We all have subtle differences in our genes (genetic variants), especially immune-system genes. This "immunogenetic" diversity has evolved to give us a vital edge in the constant war against infections. For example, you might be better at fighting some types of infection if you had a rare genetic variant. Even identical twins don't have identical immune systems, because the immune system develops, learns and changes over your whole life. If your immune system is like a guard-dog, inflammation is like its "teeth", and defends you against infections or other potential threats. However, in autoimmune diseases, your immune system has a tendency to get overexcited in certain situations, with the result that inflammation can set in where it shouldn't.

In PMR, your body isn't so good at calming down inflammation around joints, tendons and ligaments. Once that inflammation "bites", it may need medication, like prednisolone, to calm it down. Sometimes, I hear people talk about steroids for PMR almost like a fixed-term loan that you somehow pay off bit by bit, with gradually-reducing interest payments until the loan is all paid off. But PMR is not that straightforward. The immune system is there to protect you: if it thinks it sees a threat, it will react to defend you, unless there is medication on board to quieten it down. So, as the prednisolone dose tapers down, the inflammation can pop up again (PMR relapse).

What about "resurgences"? Prednisolone mimics cortisol, an anti-inflammatory steroid hormone: the idea is that prednisolone damps down inflammation – which it does very well. But prednisolone is not a perfect mimic of cortisol: the body releases cortisol into the blood in little bursts, whereas prednisolone's action is more smoothed out over the day. Imagine a forest fire on a rainy day: if the rain falls in a few brief downpours (like the way cortisol is released by the body), it won't have the same effects on a fire (inflammation) compared to a constant drizzle over the day (like taking prednisolone). After a while at lower prednisolone doses (below 5mg or so) your body starts to release cortisol more normally. Providing inflammation remains well-controlled, the return of this more normal cortisol pattern might perhaps contribute to "resurgences" or those weird but nice days of feeling totally well! But if inflammation doesn't stay well-controlled, relapses can occur.



UK guidelines suggest GPs refer people with PMR to rheumatology after two years of steroids. One reason is that, for some patients with PMR, some of the drugs we use for rheumatoid arthritis and many other autoimmune rheumatic diseases can shift the balance of the immune system to make "relapses" less likely, and "resurgences" of feeling well more likely. To rheumatologists this seems obvious, since PMR is an autoimmune disease with strong similarities to many of the other diseases we treat. For patients it can be quite a psychological blow to be told that their PMR might not "go away" after the fabled two years; charities like PMRGCAuk can provide vital support, but please keep talking to your doctor, too.

Sarah Mackie

Dr Sarah Mackie
Consultant Rheumatologist

If you have a question for Dr Sarah Mackie or want to share some news, please email **letters@pmrgca.org.uk** or write to Fran at BM PMRGCAuk, London WC1N 3XX. For ethical reasons, Sarah can't give medical advice or discuss individual cases.

RESEARCH SPECIAL EDITION

Improvements in diagnosis and quality of care for PMR and GCA patients

The research page on our website has recently highlighted the efforts at two different centres, one in Denmark and one in the UK, to improve services for patients with PMR or GCA respectively. Both demonstrate the positive impact on patients that can be made.

Improving the quality of care for people with giant cell arteritis.

The rheumatology department at Norfolk and Norwich University Hospital undertook a series of quality improvement projects. They had several concerns they wanted to resolve. They were not seeing as many referrals for GCA as they should. This could mean that patients were not being referred to hospital or were being seen in other departments of the hospital. There was no protocol for the use of steroids and other drugs, which meant that patients would be taking and tapering them in different ways depending on who they saw rather than who they were. Temporal artery biopsies were arranged on an ad-hoc basis and there was no ultrasonography available. Patients' access to appointments and medication plans was restricted and there were no follow-up specialist clinics.

Having identified these issues they undertook a review of all the literature and with mathematical modelling they developed and agreed upon a steroid regimen: "the Norwich Regimen" which is based upon the patient's height, weight and gender; introduced ultrasonography; set up a specialist clinic and appointed a specialist nurse.

As a result of this, they began to see more referrals and diagnosed GCA more frequently and securely. Whereas previously, the majority of diagnoses (17 out of 19) were made by biopsy, seven years later, less than 10% (four out of 51) needed a biopsy.

As well as being able to help more GCA patients, the cost of diagnosing patients fell from over £1,200 per patient to less than £300. Patients also receive ongoing education and support via the specialist nurse.

Fast track clinic for early diagnosis of polymyalgia rheumatica – Impact on symptom duration and prednisolone initiation

The Silkeborg Regional Hospital in Denmark conducted a retrospective study on a fast-track service for the diagnosis of PMR that they had set up in 2016. They contacted GPs to explain the referral criteria and provided a nurse for GPs to contact to arrange a referral. An appointment was arranged for any qualifying patient and the patient received a raft of diagnostic tests including a low dose CT chest examination, an abdominal ultrasound, blood tests and examination by a rheumatologist. Further tests were undertaken if required. If PMR was diagnosed, prednisolone was prescribed and tapered in a nurse-led tapering regimen.

Not only was the symptom duration prior to diagnosis reduced in the fast-track cohort – from a median 80 days in a non-fast track group to 52 days in this group – but the commencement of prednisolone before rheumatology assessment was reduced from 42% in the non-fast-track to 11% in the fast-track group. This is important because it is harder to make a diagnosis of PMR once prednisolone has begun.

https://www.sciencedirect.com/science/article/abs/pii/S1297319X21000579?via%3Dihub

These centres have shown that well-structured pathways can improve patient journeys, result in more secure diagnosis and be more cost-effective at the same time. Fast-track pathways for PMR and GCA remain few in number. But it is perhaps equally important that the rise in fast-track pathways goes hand in hand with accuracy of diagnosis as well. Especially for PMR, the Danish study has shown that fewer people needed steroids if they were assessed systematically.

To read other research articles, please look up our research page: **https://pmrgca.org.uk/professionals/medical-research/**

RESEARCH SPECIAL EDITION

TARGET

Research to help GCA

The TARGET (Treatment According to Response in Giant cEll arTeritis) Consortium – funded by the Medical Research Council – is a partnership between clinicians, scientists, industry and patients who are working together to reduce steroid toxicity and to improve the outcomes for patients with giant cell arteritis (GCA).

Their objectives cover many approaches but fundamentally, they are looking at improving tools for diagnosis and monitoring of disease so that patients who are in remission get off steroids sooner and that patients requiring treatment have better access to steroid-sparing therapies. It is hoped that improving the knowledge of how GCA and PMR develop will allow better treatments to be identified, including medications that are already used to treat other inflammatory diseases.

The MRC TARGET Partnership began in 2017 and is led by Professor Ann Morgan at the University of Leeds. Its members include universities such as Leeds, Oxford, Newcastle, Imperial College and Bristol; hospital trusts such as Leeds, Guy's and St Thomas's and Nottingham University Hospital; and industry partners such as Roche Products Ltd.

Many members will be familiar with some of the people involved, which includes, as well as Professor Ann Morgan, Dr Sarah Mackie, Professor Rashid Luqmani, Professor Justin Mason and many more. There are currently three patient partners serving on the board, one of whom is charity member Dianne Wloch who became involved after listening to a presentation about the TARGET Consortium at the PMRGCAuk AGM in 2018.

Dianne attended the first scientific meeting of the consortium later that year which included presentations from clinicians, researchers, medical students and industry partners with an interest in GCA. Following the meeting she accepted the invitation to sit on the Partnership Management Board as a patient partner. The role includes attending online board meetings, where research partners report their progress, scientific meetings, listening and contributing to discussions and providing feedback from a patient's perspective. She reads documents before distribution to the lay person and contributes to applications for research funding where appropriate.

Active research includes clinical studies, glucocorticoid toxicity, imaging biomarkers, pathogenic mechanisms and therapeutic targets and molecular diagnostics. Some charity members, currently receiving tocilizumab therapy, may have been recruited onto the GCAT Registry where data relating to their GCA diagnosis, treatment and outcomes is recorded in order to study the drug's effectiveness and safety. An in-depth explanation of the GCAT Registry and active research can be found via this link:

https://lida.leeds.ac.uk/target-2/active-research-projects/

We hope to bring you more information about TARGET's work in future editions

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Notes from the Chair – Richard Cuthbert

February 2022

As I write this, life is still dominated by Covid. Our Dundee group managed one in-person meeting before Christmas but then the regulations tightened again and we have been forced to survive on Zoom meetings alone. I am always amazed at how closely these mimic a real meeting but there is something missing. Fingers crossed that we are back together soon.

In the last issue I was looking for volunteers to take over the duties of secretary and also treasurer. I am delighted to report that David Carrott has taken on the main duties of secretary. Outgoing secretary, Michael Benneworth, took up the office in 2013 and did a tremendous amount of work for the charity. Nothing was ever too much trouble and his cheerful disposition made it a pleasure to work with him. On behalf of all our members I say thank you, Michael, and all the best in the new challenges that you are already tackling.

This success has to be balanced with our failure so far to find a new treasurer. If you are interested, or know of someone who might help, please let me know. The duties are fairly straightforward and are centred on maintaining the books and records of the charity and producing regular accounting information. Our annual income is about £6,000 and formats and templates are available to assist with the processes.

We are busy with preparations for our 2022 AGM in March which is going to be our third in succession without seeing each other in person. It seems a long time since the first disruption when the business of the 2020 meeting had to be conducted by email, but thankfully since then we have been introduced to the magic of Zoom (other brands are available!) which has allowed us to maintain a remarkable degree of personal contact within small and large groups. There are even some advantages with Zoom as regards accessibility to the meeting for members from all round the country who might find it difficult to get to Dundee, and access to speakers – we are going to benefit from an online presentation from Dr Sarah Mackie.

Earlier this week I attended an online meeting of the Cross-Party Group on Arthritis and Musculoskeletal Conditions. This is a forum of the Scottish Parliament which brings together MSPs, medical clinicians and researchers, and charities and other focus groups. The main theme was the dreadful effect of the pandemic on patient care in the field of rheumatology – increasing waiting times for consultations with GPs, consultants and specialist nurses – increasing waiting times for surgical procedures – unfilled staff vacancies. I imagine that all of these problems exist throughout the UK and across many fields of medicine. The speakers at the meeting were eloquent and persuasive, and the convener (an MSP) was absolutely on-board with what was being said and ready to tackle the government about the issues and their plans for improving the situation. I found this all to be interesting and exciting, but there was no getting away from the nagging question in my mind – can one parliamentarian persuade enough colleagues to pressurise government into allocating valuable resources from a finite pool to this one particular sector? That is an enormous challenge and I hope the convener is successful – the outcomes for our PMR/GCA community throughout the UK rely on politicians being convinced about the merits and urgency of our needs.

SUPPORT GROUP CONTACTS

Our network of groups around the country is growing!

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