PMR GCA UK
Polymyalgia Rheumatica & Giant Cell Arteritis UK

£3.50 Free to members

NEWSWIRE

SUMMER 2021
ISSUE 34

Highlights from PMRGCAuk Week webinars:

LIVING WITH GCA

POLYMYALGIA BEYOND STEROIDS

Your Story:

PMR FORCED ME TO REDUCE MY HOURS

COVID-19 AND THE IMMUNE SYSTEM

LEARN ABOUT STEROIDS AND DIABETES

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Welcome

It's been lovely to feel a sense of normality returning as lockdown rules are relaxed and I hope that many of you have been able to see family and friends again, albeit in a safe and socially distanced manner.

Likewise, there has been a sense of normality within the charity too. PMRGCAuk Week was a chance to spread the message about PMR and GCA to a wider audience and we are very grateful to our experts, vasculitis and CTD specialist nurse **Georgina Ducker** and consultant rheumatologist **Dr Vadivelu Saravanan**. Their talks, *"Living with GCA"* and *"PMR beyond steroids"* respectively, were very interesting and allowed many of you to get answers on a range of questions. If you missed the webinars, then please do catch up with them on our website or read the reports in this edition. Another popular event from the week was the launch of our photo competition for the PMRGCAuk 2022 calendar. If you have some suitable shots, there is still a little time left to enter. I was very impressed with the entries last year and look forward to seeing the winning images in due course.

We are thrilled to be making progress with our grant into PMR research that has all been made possible by the generous donation from one of our members. You can find out where we are with that project in Charity news.

Since the last edition of NewsWire we have also moved forward with the project to develop our Kent support groups. Even if you don't live in Kent, do read about what we're doing there because it may be that you can help us to get a grant for a different region which would enable us to expand support around the country.

We are in the midst of preparing for our Members' day next month. It's always a good opportunity to see familiar and new faces and to share in the work that we have been doing. I hope to see you there.

Humphrey Hodgson

Humphrey Hodgson
Chair of Trustees

PMRGCAuk Members' day

Our Members' day and AGM takes place on **Saturday, 4th September**. After the success of last year, and because of ongoing uncertainties and concerns about groups meeting, we are holding the event on Zoom. While this restricts access for some, it opens up access to members who would not otherwise be able to attend and we hope to see a good turn out again.

Details are being sent out in August. If you haven't received information on how to register by 23rd August, please email **info@pmrgca.org.uk** or phone the office on **0300 999 5090**.

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 and never delay in seeking it 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.

There have been two systematic review and meta-analysis studies about GCA.

This type of study provides the highest level of evidence about a treatment. What we mean by that is that we can be confident in the conclusions from the study. I thought it would be helpful to describe these studies in a bit of detail, as well as what the researchers found.

A systematic review can be a study by itself. It is exactly what it sounds like; the researchers systematically search through databases of published studies using something called a "search strategy". An example of a database that you could go and look at yourselves is: **https://pubmed.ncbi.nlm.nih.gov/**. A search strategy defines aspects of the questions (patient groups, treatment(s), outcomes) that you are looking at and makes sure all the different ways of expressing are included (e.g. looking for "giant cell arteritis" and "temporal arteritis"). This often leads to thousands of papers being identified. The researchers then read all the titles, abstracts (short summaries) and finally full text articles. They remove papers that aren't relevant as they go along. When they have the final list of papers to include, they grade the quality of the studies. To do this they use a published checklist that is relevant to the type of study (e.g. trials). Data is then extracted from the papers so that it can be combined into an appropriate summary of the literature. This can be a series of tables showing the results of each study and an accompanying discussion. This is usually known as a narrative synthesis.

The two studies I mentioned at the beginning combined the results for each study statistically. This is called a meta-analysis and is the best way to do it when the data is similar enough across the studies that are found. This type of analysis makes the results easier to understand.

The first study (**Giant cell arteritis: A systematic review and meta-analysis of test accuracy and benefits and harms of common treatments - Dua - - ACR Open Rheumatology - Wiley Online Library**) included 399 papers and looked at different treatment strategies for GCA. The researchers found some evidence that tocilizumab worked in reducing the rate of relapses over one year and people felt generally better on this treatment than on steroids alone. They also looked at different methods of diagnosis, but they were not able to make strong conclusions about what is best. This might be because when different approaches give different answers, we do not know which one is correct.

The second study (**Efficacy and safety of steroid-sparing treatments in giant cell arteritis according to the glucocorticoids tapering regimen: A systematic review and meta-analysis - ScienceDirect**) looked at adding an additional treatment to steroids. The researchers included 16 papers and found a benefit from tocilizumab in reducing the risk of flares over a year. The benefit seemed similar whatever steroid dosing pattern was used. They found no benefit from other drugs (e.g. methotrexate).

In both systematic reviews, the researchers expressed concern about the quality of the studies included in the review and the lack of studies replicating each other.

In conversation with Jenni Murray

We were delighted to welcome **Dame Jenni Murray** in May as part of our social calendar of events. More than 100 members attended and Jenni entertained us with a talk about her life, health and interviewing interesting people on Radio 4.

Charity News

PMR grant

We have invited applications from clinicians and/or scientists for our project grant of £50,000 to address one or more of the research priorities identified by people with PMR – pain; stiffness and fatigue; diagnosis; steroid management and self-management as discussed in the Morten et al paper found here: **https://pubmed.ncbi.nlm.nih.gov/30617599/**

The deadline for the first round submissions was 30th June, and all proposals are being reviewed and shortlisted by a selection panel comprising clinicians, scientists and lay representatives. We will make our shortlist by mid-September, with the deadline for the second round submission being at the end of October. We aim to have chosen the final project by January 2022.

PMRGCAuk becomes a NIHR non-commercial partner

NIHR, the National Institute for Health Research, is the UK's largest funder of health and care research in the country – receiving its income predominantly from the NHS research budget. It works with NHS hospitals and universities, and its main aim is to harness scientific advances into patient care.

In addition to putting NHS funds into research, NIHR plays a vital role enabling researchers funded from other sources to perform clinical research. It supports them in planning and delivering research on patients, especially if the study requires access to NHS services. It offers a study support service, which anyone planning research through PMRGCAuk will now be able to use.

To be recognised as a non-commercial partner we had to demonstrate that any research funding we award will involve open competition and high quality peer review; that the research is of clear value to the NHS, social care or public health; and that we take account of the priorities, needs and realities of the NHS, social care or public health in making decisions about the research we fund.

From now, studies we fund will be included in the **NIHR clinical research network portfolio**.

Obtaining this recognition is particularly important as we embark on the research grant mentioned earlier.

Monthly research updates

Did you know that we post recent research to our website at **https://pmrgca.org.uk/professionals/medical-research/?** We include a clear explanation of the purpose and result of each study and a link to the relevant paper (if there is one). The page is updated monthly.

Free professional membership

We offer free membership to consultant rheumatologists, opthalmologists, rheumatology nurses, doctors, in fact anyone working within these areas. Do tell your clinicians that they can register for free membership at **https://pmrgca.org.uk/professionals/professional-membership/**

Introducing Kent regional organiser

Neelam Russell

We are really pleased to introduce Neelam Russell who joined as our new Kent regional organiser (KentRO) in May after we were awarded a grant from Kent Community Foundation for a pilot scheme to support existing Kent groups and to set up two new ones.

Neelam worked for seven years as volunteers' manager with Age UK in Tunbridge Wells.

Neelam has hit the ground running and we have already sourced a new venue for Kent's Whitstable group and hosted its inaugural meeting – see Group news for more details. Dates and times for future meetings will be announced on the charity's website at **https://pmrgca.org.uk/get-support/groups/**. If you live in Kent and are affected by PMR or GCA and would like to be included on the mailing list, please contact Neelam by email: **kentro@pmrgca.org.uk** or call 0300 999 5090 (out of hours please leave your name, telephone number and reason for calling).

Two further groups will be set up by Neelam over the next six months: Dartford support group for those in the Dartford and Medway areas and Tonbridge support group for everyone in Tonbridge/ Tunbridge Wells (and over the border in Sussex).

Meanwhile Orpington group organiser and trustee, Penelope Denby, is applying for more funding from Kent Community Foundation and other charitable bodies in the area so that the pilot can continue to grow the charity's support group network.

Can you help?

Successful grant applications are one way to support the PMRGCAuk community. The Kent grant is solely to increase the number of Kent groups although members in neighbouring counties are more than welcome to join in with Kent meetings.

However, most regions in the UK have community foundations offering grants to support local organisations and registered charities. If you have experience in grant applications and would like to raise funds to set up a group where you live or more groups in your county please get in touch with us by emailing **candy@pmrgca.org.uk**.

TESCO

More money for Kent

We are thrilled to have also been awarded £1,000 by Tesco Bags For Change towards funding our Kent regional organiser.

500

Surge in new members

The last 12 months have seen an unprecedented increase in new members to the charity. Nearly 500 new members joined between June 2020 and May 2021.

Groups around

Left: Five Orpington Group members enjoy a walk in Hollydale Park in Keston

Below: Harrow and Pinner Support Group

Bottom left: Yorkshire Support Group Zoom meeting

Orpington support group

Our monthly Zoom meetings have continued and we keep in touch via a WhatsApp group. Five of us enjoyed a walk in Hollydale Park in Keston in early May with plans for more, particularly as the weather warms up. It's lovely to get together, particularly for those who don't zoom.

Yorkshire support group

The Yorkshire group has had three Zoom meetings since March and three new people have joined.

We plan to meet face-to-face in September when venues are open and fully operational. Zoom meetings will also continue. This will improve access for other members who live further afield or can not travel in to Leeds or Ilkley.

At the last meeting on 18th May, Teresa Cook organised Laura Smith of Leeds Mindfulness Co-operative to do a session on wellbeing and we all found that extremely beneficial.

Whitstable support group

Nine members met for the first meeting since lockdown. The venue was large and open and adhered to all Covid government guidelines and we were able to remove masks when seated. We had a mix of old and new members and the group was full of ideas for future meetings. Everyone was enthusiastic and delighted to meet others who could really understand some of the challenges they have been facing.

East Midlands support group

Some members have met up for coffee and other members, who have kept in touch over Zoom, are planning to meet soon. However due to the wide geographical spread of members, which makes it difficult to organise meetings, we are dissolving the group and looking to set up smaller ones in the Derby and Nottingham areas.

If you are interested in hearing more about these, please email **candy@pmrgca.org.uk**.

Brighton support group

The Brighton group zooms every six to eight weeks and we have a really positive time chatting to each other, having formed quite a close bond since March 2020.

We had contemplated a face-to-face meeting at the pub we used to meet at, for our July catch up, but with the huge rise in Covid cases in Brighton, we may postpone face-to-face and meet on Zoom once again.

South West support groups

The groups from Taunton, Portishead, Bristol and Bath have been meeting up together on Zoom every other month.

When new people contact the group, we offer them a chat on the telephone to discuss their health and advise them of the support that

the country

is available from the charity. The call is usually for about an hour.

Coventry support group

I continue to send out weekly "ramblings" to those members who have opted to receive them. These often develop into individual one-to-one emails. I am not sure yet whether we are ready to return to meeting in the hotel we used to use before lockdown since they are usually open to all members of the general public. This needs to be investigated and discussed.

Harrow/Pinner support group

Since March we have zoomed on a monthly basis and generally around 11 attend. We talk about our personal experiences and share local issues e.g. vaccination centres, osteopaths, local Zoom talks, as well as tips and gadgets on making life easier. I also update them on any news from PMRGCAuk.

We are eager to meet up again and I have been in contact with the church hall and have acquired their Covid guidelines and will contact the members when there is a plan. Hopefully a new group organiser will also be found.

Trent Valley support group

As a new group, and a small one at that, it has been challenging to get Zoom meetings up and running. However, Janice Maddock (trustee) attended a couple of our meetings which gave me much wanted support and we now have three new members.

In June we finally met face-to-face in my garden for coffee. Even better, the wife of one of the members sent us scones with jam and cream.

Spotlight on Group Organisers

Group Organiser: Ann Hollingsworth
Group Name: Coventry support group

Condition: I was diagnosed with PMR and GCA in 2012. From a starting dose of 60mg of prednisolone, I now take 6mg daily. I feel better now than I have done for years and intend to stay on that dose until my rheumatologist advises me otherwise.

How many people typically attend meetings? The group has 22 members which includes some partners. On average there are ten people at meetings.

Before coronavirus how often did your group meet? Normally once a month.

What was the format of the meetings? Our normal meetings were a chance to share news from the charity and from other members. We would often share how we were doing with regards to our health with special attention being given to newcomers. This often included discussions about steroid reduction. It was a supportive space for those feeling stressed but we would aim to be positive where possible. Occasionally we had a speaker and that would be the focus of the meeting.

How has coronavirus changed that? Clearly coronavirus brought such meetings to a sudden stop. As suggested by PMRGCAuk I emailed everyone and asked if members would be willing to share email addresses so that they could keep in touch with each other. I also began sending a weekly "Rambling" email to those who wished to receive it.

In May I held a socially distanced coffee morning in my back garden. Four members joined me and although it was cold we were fortunate that it was dry.

Why do you decide to set up a group? In early 2017 I attended a starter meeting of three interested people. I became the group leader when members chose to meet during the daytime.

How much time does it take? Writing minutes and agendas for pre-pandemic meetings was not too time consuming, the more recent "Ramblings" depend on my level of inspiration!

Does anyone else help you? Occasionally, if help is needed I ask for volunteers.

If you'd like to join the Coventry support group, please email coventry@pmrgca.org.uk

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

PMRGCA WEEK

We were delighted to welcome more than 200 members and guests to our PMRGCAuk Week webinars.

The first talk, Living with GCA, was with Georgina Ducker, vasculitis and connective tissue disease (CTD) nurse at Norwich and Norfolk Hospital.

Georgina spends about 60% of her time with giant cell arteritis (GCA) patients, working closely with our trustee, consultant rheumatologist Chetan Mukhtyar.

Georgina explained that GCA is a type of vasculitis and vasculitis means 'inflammation of the blood vessels'. In GCA it is the vessels in the head and neck that are usually affected but the upper limbs and the main artery, the aorta, can also be affected.

The causes of GCA are still unknown. Generally, the condition affects the over-50s, more commonly women and the majority of patients with GCA are of northern European descent – although that does not exclude others.

Without treatment GCA can lead to blindness, a stroke or ulceration of the scalp so it is really important that the condition is diagnosed swiftly. The damage is caused by inflammation in the blood vessels interrupting the blood supply. Steroids reduce the inflammation.

At Norwich and Norfolk Hospital, GCA patients are usually started on a high dose of 40 to 60mg of steroids per day which is gradually reduced – sometimes over several years. The aim is for the steroids to reduce the inflammation and put the GCA into remission. They follow what is known as the Norwich Regimen, a 100 week steroid reduction plan.

It is important that steroids are not stopped suddenly; reduction must be done gradually to reduce the risk of adrenal insufficiency and allow the body's own cortisol mechanism to spring back into action.

At Norwich and Norfolk Hospital, patients on treatments are reviewed regularly and offered appointments initially at three monthly intervals. As their condition stabilises the interval between appointments is increased but they are given a contact number and encouraged to call if they need to talk to someone.

As the steroid dose is reduced there is always the risk of a relapse and if this happens steroids are reintroduced at a higher dose, often together with another drug such as methotrexate or tocilizumab.

Patients are frequently on multiple medications which treat side effects. It is important to guard against osteoporosis, so patients need to take something to protect their bones, and stomach ulceration, so protecting the stomach lining is also important. Throughout the treatment, regular monitoring for diabetes is carried out and patients are advised to have regular eye checks to detect early conditions such as glaucoma and cataracts.

Patients often experience weight gain, mood changes, trouble with sleeping and fragile skin; good skin care is really important to maintain skin integrity and reduce risk of cuts to protect against ulceration. Fatigue is another really common problem for patients with GCA. Georgina advised that although the natural reaction is to rest, it is better to do some small activity little and often. It can make the fatigue more manageable. Keeping active can also help to manage your weight, improve your bone strength and contribute to lower blood pressure.

When patients have successfully completed treatment and no longer need to be seen regularly, Norwich and Norfolk Hospital has a fast-track pathway. If any symptoms recur patients can call in and be seen promptly.

The second webinar, with Dr Vadivelu Saravanan, consultant rheumatologist at Queen Elizabeth Hospital in Gateshead, was a very comprehensive talk about steroids, covering recent PMR research which helped us to understand the challenges and importance of getting a good diagnosis and treatment as quickly as possible.

Below is a very summarised account of his talk; if you get the chance, do watch the webinar in full at **https://pmrgca.org.uk/pmrgcauk-week-june-2021/**

Dr Saravanan explained that the British Society of Rheumatology guidelines for polymyalgia rheumatica (PMR) recommend a plan for steroid dosing and tapering, however there is no research evidence to support the tapering plan; most rheumatologists start prednisolone at 15mg per day, dropping to 10mg within a month, thereafter reducing by ½ or 1mg per month. This plan takes 18 months to complete, however many patients relapse. Hence Professor Kirwan in Bristol recommends staying on 10mg for a year before tapering over the next year. Whilst this prevents relapses, the cumulative

prednisolone dose will nearly double, thereby increasing side-effects.

In only the last three years we have learnt more about how long people take prednisolone in real life.

Eric Matteson at the Mayo Clinic published a study of 359 patients in 2017 and found that at the 18-month-mark most patients were still on 5mg and it took until nearly six years to discontinue use. On a positive note, there was no increased risk of side effects except for cataracts.

A more recent German national database study found that one in four people are still on prednisolone treatment after three years but the majority of patients manage to bring the dose below 5mg after 18 months. Difficulty in controlling PMR in the first year predicts how long you are going to be on prednisolone – so if the first year is ropey then you may be on steroids for at least three years.

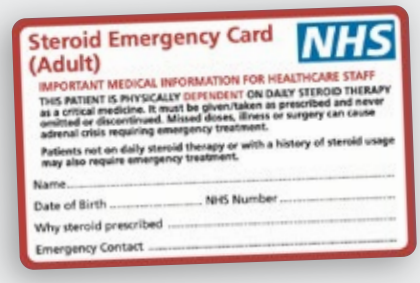
Last year the Primary Care Research Group at Keele University published the PMR Cohort 2 year study. They identified five different groups of people based on the responses to prednisolone treatment. Overall, 50% of people starting prednisolone saw a good recovery in their symptoms within 1-2 months. There were two groups of concern: a group that made a less than partial recovery, so the stiffness lessened to some extent and then they continued to get worse over the next 18 months; the other group, less than 10%, showed no recovery at all so it is doubtful whether this was polymyalgia in the first place.

Rheumatologists question whether these five groups of people presenting with typical polymyalgia symptoms actually all have polymyalgia. Half of them may have a mix of other conditions – like fibromyalgia, wear and tear of the neck, lower back and shoulders. And probably one third of people have polymyalgia plus something else such as rheumatoid arthritis, temporal arteritis or GCA. Of the third, at least 10% will go on to have temporal arteritis or GCA. The doctors can't tell at the beginning of starting steroids who will belong to which category. At 5 – 7mg of prednisolone, things become more apparent. Dr Saravanan thinks all patients need a six month review of their diagnosis and response to prednisolone.

Some patients, who respond to 15mg of prednisolone but suffer as soon as the dose is reduced, probably have something other than PMR. At high doses prednisolone cures many illnesses including depression, chronic pain from fibromyalgia etc. For a short while you feel better but it is often temporary. Dr Saravanan explained that he would prefer not to keep people on more than 10mg of prednisolone for too long because firstly it masks other problems which were never PMR and secondly because of the risk of side effects.

Steroid side-effects include diabetes, increased blood pressure, thinning of the bones and skin, muscle weakness and weight gain. Diabetes and weight gain can improve, but the bone/skin thinning tends to remain. The longer you are on steroids (more than two to three years), the more likely the effects will persist.

One of the approaches Dr Saravanan discussed for reducing the duration and side effects of prednisolone is using the drug methotrexate in the following circumstances: after one year if you're struggling to come off steroids and had more than one relapse; multiple side-effects from steroids within six months; other joints inflamed and when 15mg of prednisolone is not enough to treat the PMR. It is typically prescribed at 15mg per week and requires a monthly blood test to monitor blood count and liver function.


Steroid Emergency Card (Adult)

NHS

IMPORTANT MEDICAL INFORMATION FOR HEALTHCARE STAFF

THIS PATIENT IS PHYSICALLY DEPENDENT ON DAILY STEROID THERAPY as a critical medicine. It must be given/taken as prescribed and never omitted or discontinued. Missed doses, illness or surgery can cause adrenal crisis requiring emergency treatment.

Patients not on daily steroid therapy or with a history of steroid usage may also require emergency treatment.

Name .....

Date of Birth ..... NHS Number .....

Why steroid prescribed .....

Emergency Contact .....

The NHS recommends that anyone who is taking prednisolone for more than a month should carry the emergency steroid card and keep carrying it for a year after finishing prednisolone. The card is available from the PMRGCAuk website, **https://pmrgca.org.uk/steroid-emergency-card/** and from pharmacies, GPs and hospitals.

Dr Saravanan discussed "Sick Day Rules" which are used by some doctors. With this particular guidance, if you are on a low dose of prednisolone (typically under 10mg daily) and you have an infection or fever, your GP or hospital doctor may advise you to increase the dose of prednisolone and split into two doses. This is to replicate what your body would have done had you not been taking prednisolone.

We would like to thank Georgina Ducker and Dr Saravanan for giving up their time to come and talk to us during PMRGCAuk Week.

See **https://pmrgca.org.uk/pmrgcauk-week-june-2021/** for questions and answers from Dr Saravanan's webinar.

Please note that different clinicians may advise different treatment plans. Do not alter your dose of prednisolone without discussing with your clinician first.

Cards and calendar competition

We launched our PMRGCAuk photo competition during PMRGCAuk Week in June and the closing date is fast approaching: 22nd August. The winning images will be chosen for either the 2022 Calendar or a selection of notelets. If you have any suitable images – nature, pets, sunsets etc – and they are greater than 500kb in file size and you'd like to enter, please email them to **cards@pmrgca.org.uk**

Calendars will be available to order from 1st September. Please email **cards@pmrgca.org.uk** with details of quantities. They will be priced at £7.95 plus P&P (P&P will vary depending on the quantity ordered). We will advise you of the total and make arrangements for payment.

smile.amazon.co.uk

Smile and raise funds for PMRGCAuk

Some of you have already signed up to Amazon Smile which donates a percentage of your purchases through Amazon to your chosen charity. If you make purchases on Amazon, please register with Amazon Smile to make sure any donations come to us. This link will take you to our charity page on Amazon **https://smile.amazon.co.uk/ch/1128723-0**

COVID-19: WHEN THE IMMUNE REGULATION GOES WRONG

Escaping the 'horror autotoxicus'

In March, Professor Bhaskar Dasgupta talked to us about the effects of Covid-19 on our immune system. Here he provides a summary of his talk.

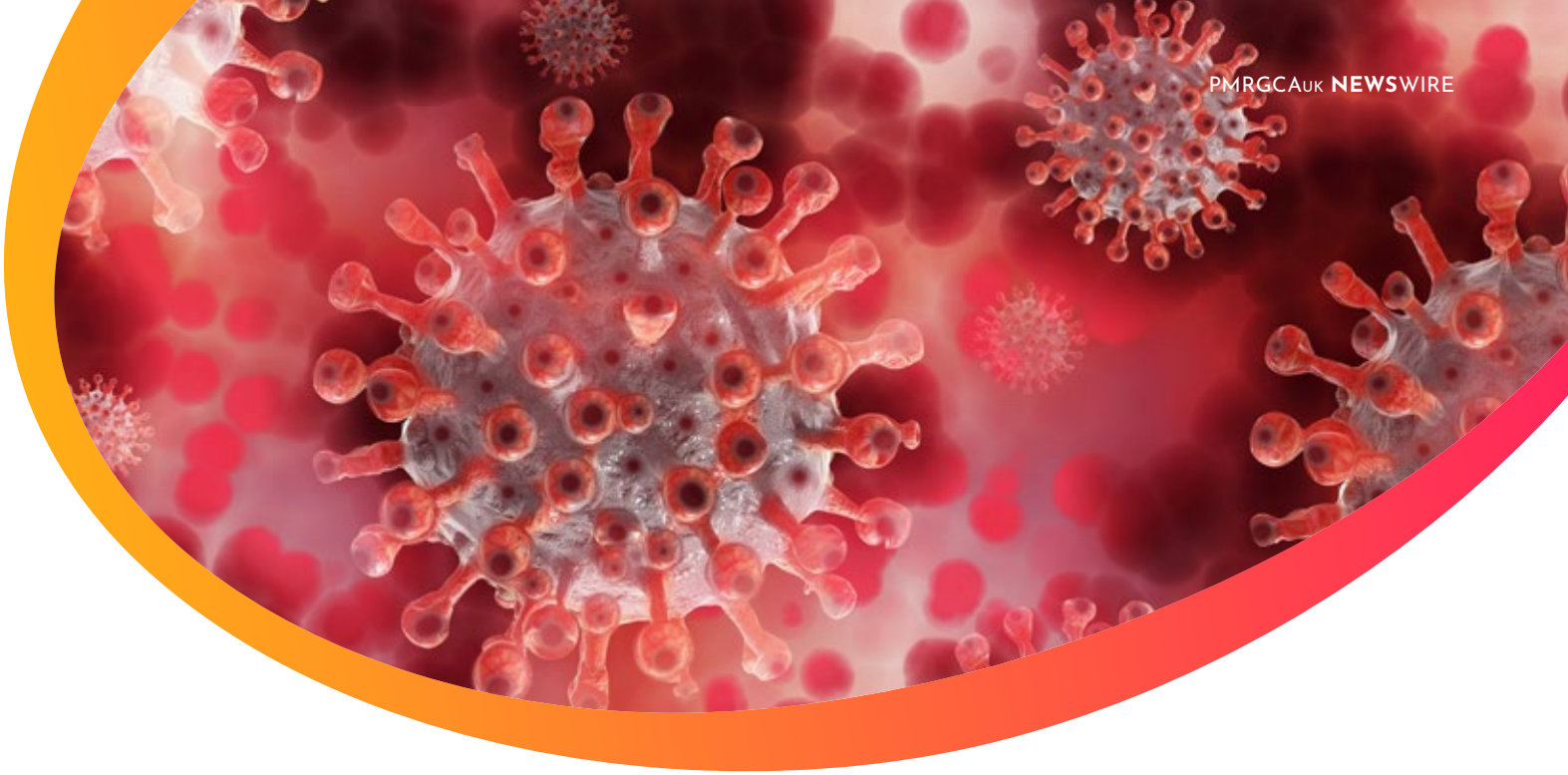
The coronavirus pandemic has cast its shadow across the world for 18 months. It has focussed attention on our immune system and how it responds to the virus; showing us that a friend can sometimes turn foe. We have been aware how the immune system can cause damage and even death, the 'horror autotoxicus' proposed by Nobel Prize winning immunologist Paul Ehrlich in 1908 – when a disconnected immune response runs unchecked. We have seen an explosion of research to generate protective immunity with different vaccines and to develop treatments with anti-viral and anti-inflammatory medicines.

Covid-19 is caused by the coronavirus SARS-CoV-2. In March 2020, Covid-19 was declared by the World Health Organization (WHO) a pandemic. As of 31st May 2021, there were 170.3 million cases, 3.54 million deaths and 1866.24 million doses (UK 65 million) of vaccines administered.

Serious Covid infection by the wily coronavirus is mediated through four main steps that can be compared to the four horsemen of the biblical apocalypse. The first horseman is the viral spike protein binding to cells in our upper airways to trigger immune responses. The **innate response**, also called natural or inherited, is non-specific and designed to work quickly, as opposed to **adaptive response** which is learned, specific to a virus and takes weeks to develop.

Innate responses, the first line of defence delivered by white blood cells, are triggered when pattern recognition receptors on these cells (the immune spotters on watch towers) recognise patterns of infective viruses and sound the alarm. Yet, the clever coronavirus can camouflage its tell-tale patterns and fool the spotters of the innate immune system. This allows it to steal inside the citadel and alarm bells are sounded too late after the enemy is already within. The body then mounts a panicked, uncoordinated response, which results in inflammatory substances causing damage to lung and other vital organs such as the kidney and heart. This is the second horseman of the viral apocalypse.

Chaos quickly turns to more chaos through endless feed forward loops giving rise to a perfect cytokine storm. Uncontrolled inflammation, poor blood flow, sticky blood vessel walls and circulating virus all engage in an unholy alliance to cause blood clots to form along the veins of the lung and to escape into the wider circulation. The battle is truly joined now by these third and fourth horsemen, making it an uphill battle for vulnerable people, older people with medical conditions, cancers or those taking specific medications.



Such severe Covid immune dysregulation can be treated with steroids – to reduce the inflammation in the lung in Covid pneumonia. Dexamethasone (a steroid available to the poorest countries) has been shown to reduce deaths, in severely ill patients needing oxygen or being supported by mechanical ventilation. Other agents that are effective by mitigating auto-inflammation include tocilizumab (which blocks the inflammatory mediator interleukin-6 and is used in autoimmune conditions such as giant cell arteritis) as well as other drugs called JAK inhibitors.

This apocalyptic scenario of hyper-inflammation, however, is the exception. In most cases the immune system can bring the virus to heel after a minor illness or even without symptoms, which presents its own danger of transmission to more vulnerable and susceptible people.

Vaccine research is trying to capture the four horsemen by engaging other immune cells to activate the more specific **acquired immunity** – acquired in response to a stimulus called antigen. The antigen used in most vaccines is the spike protein which the virus uses for the initial binding to the ACE2 receptor on surfaces of the airways and lungs and to gain entry inside cells. All vaccines rely on two delivery arms of response to provide protection. Humoral immunity secretes antibodies to fight against antigens, whereas cell-mediated immunity secretes cytokines to attack the infection. Humoral immunity is rapid or quickfire in its action against invaders, while cell-mediated immunity shows delayed but consolidated action and long-term protection. Both can be activated by coronavirus infection although questions remain as to what extent the antibody response mounted by those exposed to Covid coronavirus protects against future infection.

Several vaccines are now approved that provide protection against Covid-19 infection and its complications. They range from the mRNA vaccines (Pfizer and Moderna), inactivated whole viruses, viral subunits, to virus vectors (such as the Oxford Astra Zeneca). Virus vectors are typically adenoviruses that have been engineered to carry a payload of genetic material to make the Covid-19 virus spike glycoprotein.

The vaccines appear to be remarkably effective (especially after both doses) in protecting against serious disease and deaths and symptomatic infection and to a lesser extent against transmission. They appear to be the major way out of this pandemic (including against emerging variants), and it is important to note that their risk/benefit analysis is overwhelmingly in favour of safety. There are few contraindications to vaccination and vaccines are safe in the context of immunosuppression. However, no vaccine is 100% preventative, and it is important to follow current public health rules and advice.

There are many important questions about the disease that remain. For example, why is the disease often severe in older people, and rarely in children? And why do we see differences in disease severity between males and females, and between different racial and ethnic groups? What is the impact of other risk factors such as poverty and deprivation, smoking status, body weight, pre-existing health conditions and medications on Covid-19 susceptibility and infection? In terms of rheumatological therapies there seems to be less concern. It is unlikely that most DMARDs and biologics confer increased risk except for long-term high dose steroids (prednisolone > 10mg daily).

Members' corner

A warm welcome to all our new members and thank you to Dorothy Rowley who sent in her story.

YOUR STORY:

PMR FORCED ME TO REDUCE MY HOURS

Dorothy Rowley, 59, shares her experience with us

I was leading a full and busy life with a job in HR I really enjoyed and regular gym sessions, when I was diagnosed with PMR aged just 56.

In December 2018 I developed a really bad pain in my left thigh which my GP put down to a bad muscle strain. The pain worsened and spread to hips, legs and neck. When I went back to the GP in the January, she took some bloods and these came back as high ESR and CRP and very low vitamin D. She referred me to a rheumatologist, with the earliest date on the NHS at least 10 weeks away.

In the meantime, the pain and stiffness became unbearable: I had difficulty dressing and getting up from the toilet and my legs felt like concrete and I could only climb the stairs on all fours and walk with the aid of a stick.

Desperate, I paid to go private. The rheumatologist diagnosed PMR and put me on steroids straight away. They worked their magic and within 24 hours I could manage the stairs again.

The relief of being in less pain and being more mobile was great but the psychological impact of the diagnosis was huge. Coming to terms with being diagnosed with a chronic disease which could last anywhere from twelve months to five plus years was difficult to get my head around. Friends and family rallied round and were supportive but once they see you no longer using a stick and with big rosy cheeks (thanks to steroids) some think "you're better".

I experienced various short term side effects from the steroids: blurred vision, depression and anxiety, hot flushes and excessive sweating and the dreaded insomnia. Being told at a routine optician appointment that I had the first signs of cataracts was the icing on the cake.

My employer was not accommodating in terms of me going part-time. I challenged it but ultimately I could not face the battle with them as well as with PMR. Fortunately I was successful in finding another role but have had to reduce my hours. As an HR professional, it has made me realise just how many people are living with autoimmune conditions and hidden disabilities and their daily struggles whilst on the outside they look completely well.

Tapering is generally going well. I've never been pain free and still struggle to walk more than 45 minutes at a time (and some days even less).

Some days are better than others physically and psychologically; the hardest part is not knowing until you wake up what type of day you're going to have, which means it's difficult to plan ahead. I cope by ensuring that the days I feel better I enjoy as much as possible and on a bad day I tell myself that this won't last forever.

PMRGCAuk and its forum, HealthUnlocked, have been my rock. The Zoom webinars and meetings over the last 12 months have been fantastic and it feels as though there is always someone to 'listen' on the forum – only people with PMR can truly relate to what this illness feels like.

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

Linda from Dorset asks:

"I take steroid tablets, and I'm worried about developing diabetes."

Dear Linda, first things first: what is diabetes? Well, your body needs to have a certain level of glucose ('sugar') in the blood (around 5-7mmol/L). All the cells in your body need a supply of sugar to stay alive. That sugar can get into your blood in two ways: from your food and drink, or released from energy stores in your body. A hormone called insulin helps cells take up sugar, where it can either be used straightaway or packed away for later, as energy storage molecules. But if that blood sugar level stays too high for too long, we call that diabetes: or, to give it its proper name, diabetes mellitus or DM for short. Having too-high blood sugar levels causes various problems: for example, in the short term it makes it harder for your body to fight infection, and in the long term it can increase your risk of heart disease and strokes.

There are two main types of DM: type 1 and type 2. Type 1 is an autoimmune problem where the body destroys the cells that produce insulin and usually affects young people, although it can occur at any age. It is treated with insulin injections or an insulin pump. In type 2 DM, you can still make insulin, but the body doesn't respond to its signals so well due to resistance to its action, something that is called insulin resistance. So when you eat a meal, you get a spike of high sugar as the glucose enters your blood but then doesn't get taken up fast enough by the cells. Type 2 DM can usually be controlled with diet and tablets; most patients nowadays with Type 2 DM won't need insulin.

Type 2 DM tends to creep up on you in later life, often preceded by some years of pre-diabetes. Risk factors for pre-diabetes or type 2 DM include being overweight, previously having had diabetes during pregnancy when you were younger, or having close relatives with type 2 diabetes. There's a nice risk score on the Diabetes UK website: **https://riskscore.diabetes.org.uk/start**. Many GP practices now include HbA1c as part of health check-ups. This is a blood test that reflects your average blood sugar levels over the past three months. Less than 42 is the healthy range. Over 48 indicates diabetes. In between 42 and 48 is the pre-diabetes range.

If you are already prone to insulin-resistance, steroid tablets can make that worse. This can push up your blood sugar levels to the extent that you are classified as having diabetes. The bigger the steroid dose, the more of a problem this can be. However it's important to say that only a minority of people taking steroids develop diabetes.

High blood sugar levels can fool your kidneys into passing too much urine: you might notice feeling thirsty or a dry mouth. High blood sugar is also one of many possible causes of blurred vision – one reason why anyone with PMR or GCA who develops blurred vision should get this checked out by a doctor. Blood sugar levels can be checked either with a simple fingerprick test or a blood test that is sent to the lab.

What can you do to reduce your risk of high blood sugar levels while you take steroids? The first thing is to follow your doctor's advice about steroid dosing: don't take more than prescribed unless your doctor says it's ok. Secondly, reduce the sugar content of your diet. Beware hidden sugars in drinks and processed foods. Thirdly, exercise! This helps your muscles take up sugars and helps keep your heart healthy.

With modern lifestyles we probably could all do with reducing the amount of sugar in our diets and being more physically active – you may find you notice health benefits beyond the numbers on your blood tests!

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.

Dear PMRGCAuk,

I want to thank you for the programme on how to reduce steroid dosage down to zero.

I have been following it since November 2020 and have reduced my dosage from 15mg to 6mg by the end of this month (April). From there I will progress more slowly as I reach the lower dosages. I tried to follow my GP's advice but always encountered pain within a few days but no pain at all with your method.

I cannot express how grateful I am.

J. Heyland

John Heyland

A link to various tapering reduction programmes can be found on our website at **https://pmrgca.org.uk/information-and-advice/resources/**. Scroll down until you get to "Steroid taper app". The slower plans are to be found at the bottom of the list – look out for DSNS and DorsetLady's versions.

Pmr Gca SCOTLAND

Helpline
0300 777 5090
www.pmrgcascotland.com
Registered Scottish Charity No: SC037780
7 Hamilton Place, PERTH, PH1 1BB

Notes from the Chair – Richard Cuthbert

With the lack of social mixing (as I write) one can imagine that not much is going on anywhere, particularly when I remember that it is over a year since I took up post and yet I have not managed to visit any of the support groups around the country – indeed I haven't even been able to meet up with my local group. This is a mistaken impression, however, and there has really been quite a lot happening. The most important activity is the continued operation of our helpline by a dedicated team who quietly offer a sympathetic ear and give help to patients at a time when they are in need of support. We all know what a comfort it can be when you first talk to somebody who understands about PMR and GCA.

Then there is the success of the series of online meetings which ran through autumn and spring. I was pleasantly surprised by how personal they could be and how close they came to replicating a meeting in person. A bonus was the geographical spread of participants who came from the rural mainland, the islands, other parts of the UK as well as our more regular local group stalwarts. Holding the meetings on a Saturday morning also seemed to be a success and it will be a challenge to see if we can somehow integrate these bonuses into our future strategy when physical meetings are able to resume.

Annual meeting

For the second year running we were unable to hold our AGM in person. Last year there was a late cancellation as lockdown was introduced and we simply covered the administrative aspects by email. With much more time to prepare, and the technical wizardry of David Carrott and Michael Benneworth, we were able to present a full programme online.

Our first speaker was Dr Anna Ciechomska, a consultant rheumatologist. She talked about diagnosis and treatment of GCA with particular reference to the fast-track pathway operating in Lanarkshire. This was pitched, in my opinion, at a perfect level which I would describe as semi-technical. We as patients are not medical professionals, but we tend to have picked up a fair bit of knowledge and can cope with a reasonable degree of technical information. When we hear about such successful initiatives I think patients throughout the whole of the UK are asking why the fast-track programme is not operating in every health authority across the country. That is a target that the charities do not lose sight of!

The second presentation was from Dr Dan Pugh whose work concerning new imaging techniques I mentioned in the winter edition of NewsWire. Once again it was brought home to me that we never stop learning about PMR/GCA even after, in my case, nine years. On this occasion my ignorance concerned GCA which I have always considered to be connected with the temporal artery, eyesight, tender scalp etc – the classic symptoms we learn to look out for.

Dan explained that GCA can occur throughout your body and often does not exhibit what to us are the classic symptoms. This makes diagnosis extremely difficult and thus his project is looking at scanning techniques which, if undertaken at an early stage, can highlight unseen arterial inflammation throughout the body and allow prompt and targeted treatment.

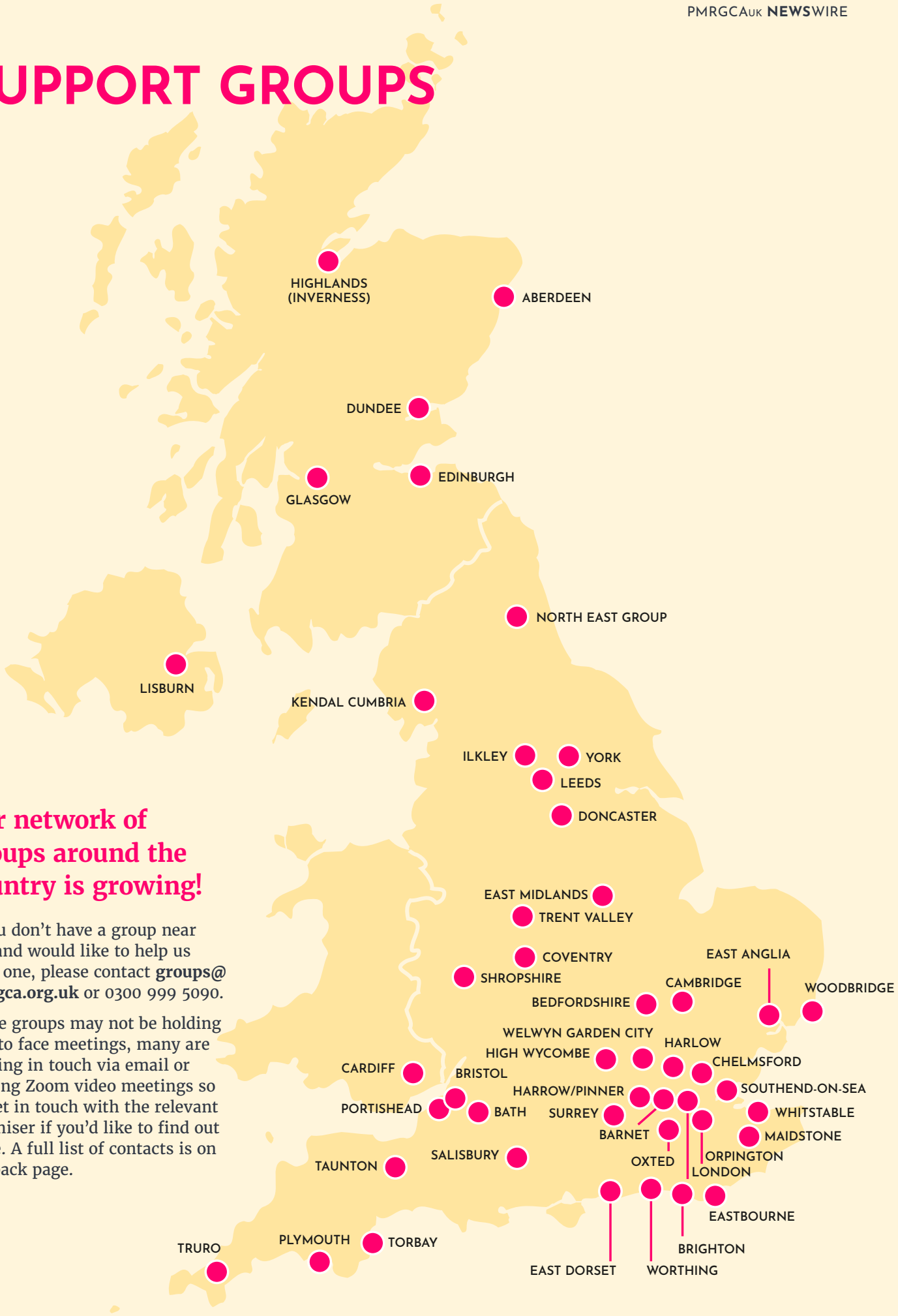
Our business meeting passed without incident and brought the event to an end.

Support groups

We were sorry to lose the services recently of Nessie Shields who spent 11 years as organiser for the Glasgow group. We wish her well in her new home up north and we welcome Marie Hannigan who has taken over that position.

I am excited to report that we are looking to establish a new group in the South West of Scotland. This follows an approach from a volunteer willing to act as organiser and we will be contacting members in that region to see if there is enough interest to start a group which might be based in Dumfries. Please feel free to contact me if you are interested but haven't heard anything more about it – **chair@pmrgcascotland.com**.

SUPPORT GROUPS



Our network of groups around the country is growing!

If you don't have a group near you and would like to help us start one, please contact **groups@pmrgca.org.uk** or 0300 999 5090.

While groups may not be holding face to face meetings, many are keeping in touch via email or holding Zoom video meetings so do get in touch with the relevant organiser if you'd like to find out more. A full list of contacts is on the back page.

SUPPORT GROUP CONTACTS

Our network of groups around the country is growing!

SCOTLAND (Scotland is an independent organisation)

PMR-GCA Scotland
Contact: Richard Cuthbert (Chair)
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Glasgow
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Kendal (Grange over Sands)
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