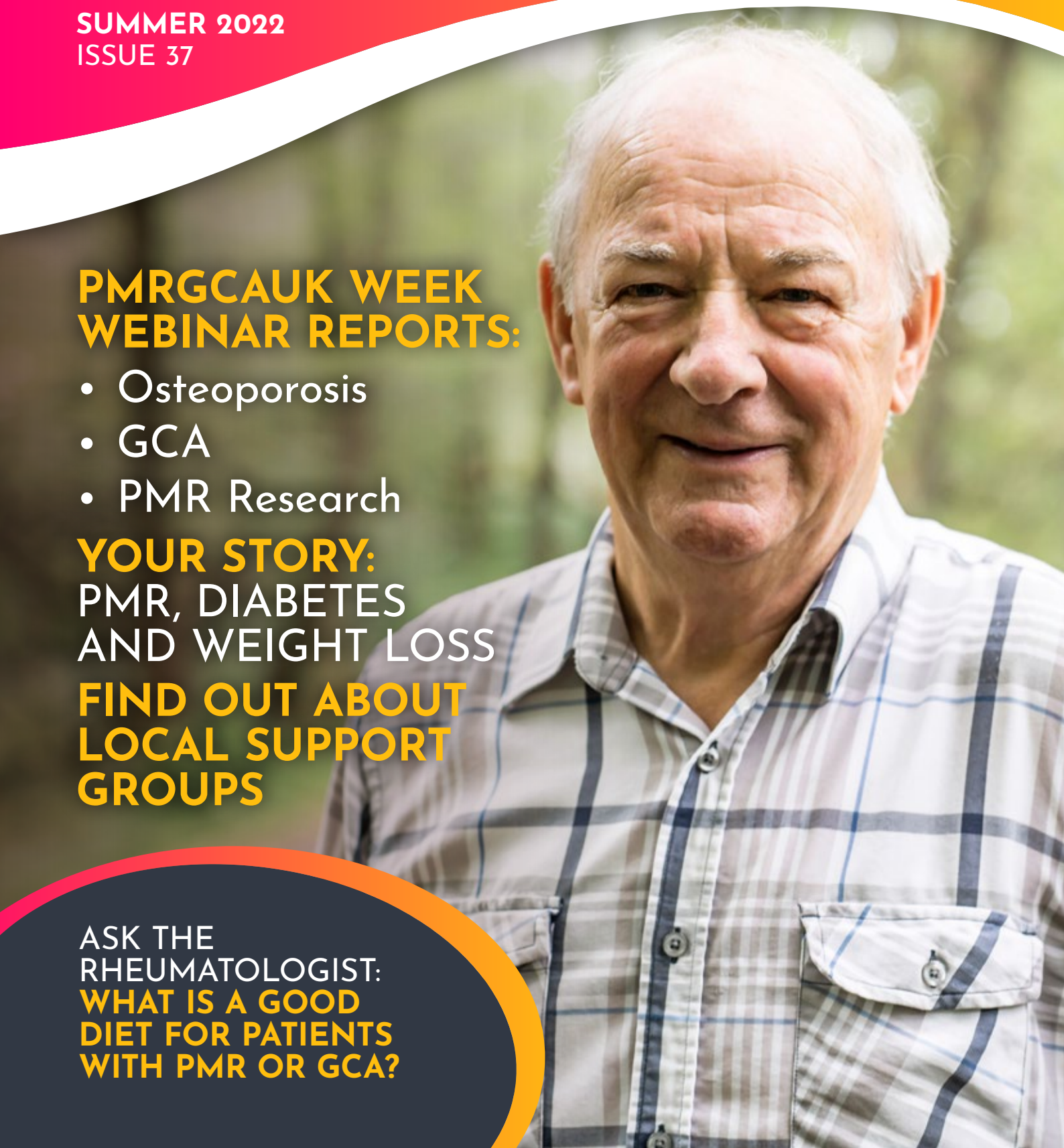
PMR GCA UK
Polymyalgia Rheumatica & Giant Cell Arteritis UK

£3.50 Free to members

NEWSWIRE

SUMMER 2022
ISSUE 37



PMRGCAUK WEEK WEBINAR REPORTS:

- Osteoporosis
- GCA
- PMR Research

YOUR STORY: PMR, DIABETES AND WEIGHT LOSS

FIND OUT ABOUT LOCAL SUPPORT GROUPS

ASK THE RHEUMATOLOGIST:
WHAT IS A GOOD DIET FOR PATIENTS WITH PMR OR GCA?

CONTENTS

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Welcome

It's always nice reflecting back on the latest PMRGCAuk Week knowing that we have helped more people to learn about various aspects of PMR and GCA. Knowledge not only helps people to manage their condition better but can also be extremely beneficial for enabling a patient to advocate for themself and to manage their expectations. Eg Should their PMR really be gone inside two years?

This year it has been particularly rewarding as not only have we heard from experts on the subjects of PMR and GCA, but we teamed up with the Royal Osteoporosis Society to learn more about osteoporosis – a condition that is estimated to affect over three million people in the UK – which is a particular concern for patients on corticosteroids.

If you missed that webinar and you are now at a very low dose of prednisolone and think it may not apply to you, I do recommend that you read the report on it, as bone health is important to us all.

In contrast, I was deeply saddened to hear of the sudden and untimely death of a former colleague and loyal supporter of our charity, Professor Justin Mason. I had known Justin for many years and his work and research in the field of vasculitis has been of huge benefit to patients with PMR and GCA and his loss will be keenly felt by all. Our tribute to him gives a brief insight into what he achieved in his working life.

On a happier note, there is a response from Dr Sarah Mackie on the subject of what diet should patients on steroids be eating – I think this will be of interest to many of you and hopefully you will be inspired by her words (and perhaps the weather!) to be eating more salads and vegetables.

In September, we will be hosting our AGM and Members' Day, with more speakers for you, and I look forward to seeing many of you there.

Humphrey Hodgson

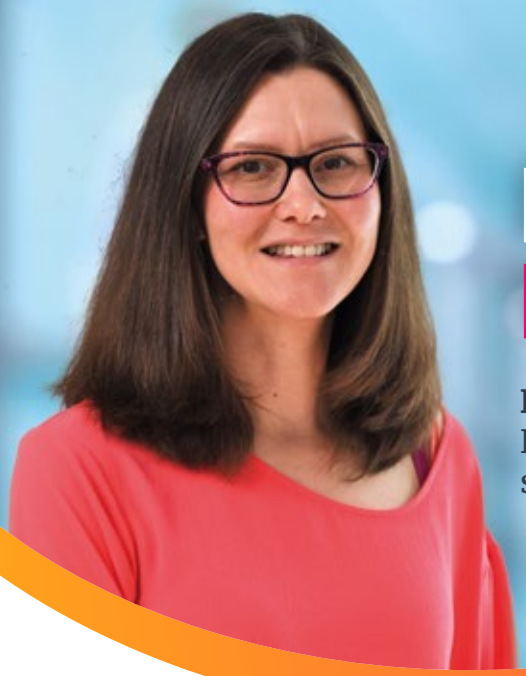
Humphrey Hodgson
Chair of Trustees

Don't forget: PMRGCAuk AGM and Members' Day is Saturday 10th September 2022

The event will be online again this year and we will welcome two guest speakers: Dr Sarah Mackie and Dr Jo Robson.

You should already have received details of how to register, if not, please contact **maria@pmrgca.org.uk** or simply register at **info@pmrgca.org.uk**. Further details can also be found on our website.

10 SEP



RESEARCH ROUND UP

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

There have been quite a few research papers published since the last issue of NewsWire. I have selected some highlights that I think give hope that research into PMR and GCA is picking up pace and might offer some new treatment options in the coming years.

To start with, there is a small trial of a drug called mavrilimumab for GCA[1]. Patients were all given a standard reducing dose of steroids over six months and were then randomly assigned to either mavrilimumab or a placebo drug as well. From this trial, mavrilimumab appears to be safe and to reduce the number of flares in people with new GCA, and in people whose GCA was difficult to control. It is a very small, "phase 2", study though, so more work will be needed before it is likely to be available.

Similarly, a protocol has been published for a trial of methotrexate as a treatment for PMR[2]. The trial will look at using the drug with steroids over 16 weeks compared to using steroids alone. It will be for people with new PMR and will take place in the Netherlands. It will complement the STERLING trial in the UK that is looking at methotrexate for people with PMR who have experienced a relapse[3].

If you are going to do a clinical trial to see if a new treatment can help people with PMR, you need to know that you are improving things that are important to those people. The PMR-Impact Scale has been developed by working closely with patients to find out what matters and has been tested to make sure it works as it should[4]. There is still some more work to do, but it is another step forwards for research.

I must also mention the piece[5] that Humphrey Hodgson, PMRGCAuk chair of trustees, wrote about the "Getting it Right First Time" (GIRFT) report[6]. This report suggested most PMR patients do not need to see a rheumatologist. With a recent review of research studies[7] of people with PMR reporting that up to one in four might have 'sub-clinical' (hidden) GCA, it is important we don't make assumptions when there is a lack of research evidence.

Footnotes

1 **Efficacy and safety of mavrilimumab in giant cell arteritis: a phase 2, randomised, double-blind, placebo-controlled trial - PubMed (nih.gov)**

2 **Polymyalgia rheumatica treatment with methotrexate in optimal dose in an early disease phase (PMR MODE): study protocol for a multicenter double-blind placebo controlled trial - PubMed (nih.gov)**

3 **STERLING · CTRU Leeds Research Portal**

4 **Development and psychometric evaluation of the PMR-impact scale: a new patient reported outcome measure for polymyalgia rheumatica - PubMed (nih.gov)**

5 **Getting it right for polymyalgia rheumatica | Rheumatology | Oxford Academic (oup.com)**

6 **Layout 1 (gettingitrightfirsttime.co.uk)** (see page 37 of the report)

7 **Subclinical giant cell arteritis in new onset polymyalgia rheumatica. A systematic review and meta-analysis of individual patient data - ScienceDirect**

Update on research grant

Dr Max Yates, who was awarded the PMR research grant earlier this year, has now interviewed and appointed the data scientist who will be working on the GP data for the project. Among the 23 million people registered within the available GP dataset there are 150,000 with PMR – with around 8–9,000 people diagnosed each year. This puts PMR in the same ballpark as rheumatoid arthritis.

The research will look at how steroid prescriptions differ, and how this can affect outcomes such as fragility fractures, unplanned hospital admissions and whether people are being prescribed appropriate PPI and bone protection.

Dr Yates said, "I'm looking forward to our findings helping to improve the standard of care for people living with PMR".

Grant for training

We were pleased to receive another grant of **£1,500** from the James Tudor Foundation for training for our helpline volunteers.

CHARITY NEWS

Trustee News – Welcoming new trustee

We are very pleased to welcome new trustee, Dr Vanessa Quick – a consultant rheumatologist at Bedfordshire Hospitals – who some of you will remember gave a fantastic presentation on GCA at our AGM and Members' Day in 2020.

Dr Quick studied medicine at Cambridge and University College London. She did her specialist rheumatology training in the Bristol and Bath region, where she worked with Professor John Kirwan who first sparked her interest in GCA and PMR and guided her to write her first publications in this area. In 2016 she was awarded a GCA travelling fellowship with Professor Bhaskar Dasgupta at Southend who has continued to mentor and support her since. She leads Bedfordshire Hospitals' ultrasound-driven GCA fast track diagnostic service and looks after many of the trust's patients with GCA and PMR. She is also a member of the GCA specialist panel for the East of England which approves the use of the biologic drug tocilizumab for patients with relapsing or refractory GCA. She performs her own ultrasound scans for GCA diagnosis, regularly teaches at national and international GCA ultrasound training courses and helped to develop the British Society of Rheumatology e-learning module for GCA ultrasound. She has published book chapters, review articles and research on GCA and PMR and her work on GCA fast track pathways has won a British Society of Rheumatology award. Her current research interest is on improving doctors' decision-making in GCA diagnosis. When not at work she enjoys time with family and friends, Pilates, renovating her home, and spending time in the sea with her husband and children.

Introducing our new admin assistant

We are also really pleased to introduce **Maria Millan** who joined us in April three days a week (Tuesday to Thursday) as maternity cover for 12 months. She has a wealth of experience working in the charity sector, having worked at Action for Blind People for 23 years. As well as that, she volunteers for several charities including the Crusoe Club for blind and visually impaired people and Frank's club which is for men over 60 with health issues. You can contact Maria on **maria@pmrgca.org.uk**

Groups around the country

Dartford Support Group

The Dartford group had an excellent talk and demonstration by Karen Larkin who is an art therapist from Centrepieces Art Project. Karen demonstrated how arts and activities can promote wellbeing and offer a form of therapy. She showed the group how to make designs using Zentangle (abstract design using black ink and pencil) and turn these into cards. They all enjoyed the experience and had fun producing something that they didn't know existed before.

In May, they enjoyed a fabulous visit to Coolings Garden Centre. The day began with tea, coffee and biscuits in the Coolings cafe. Afterwards, the group were given a 'backstage' tour of a very busy garden centre that is supported by robotics. The group raised £90 for the charity.

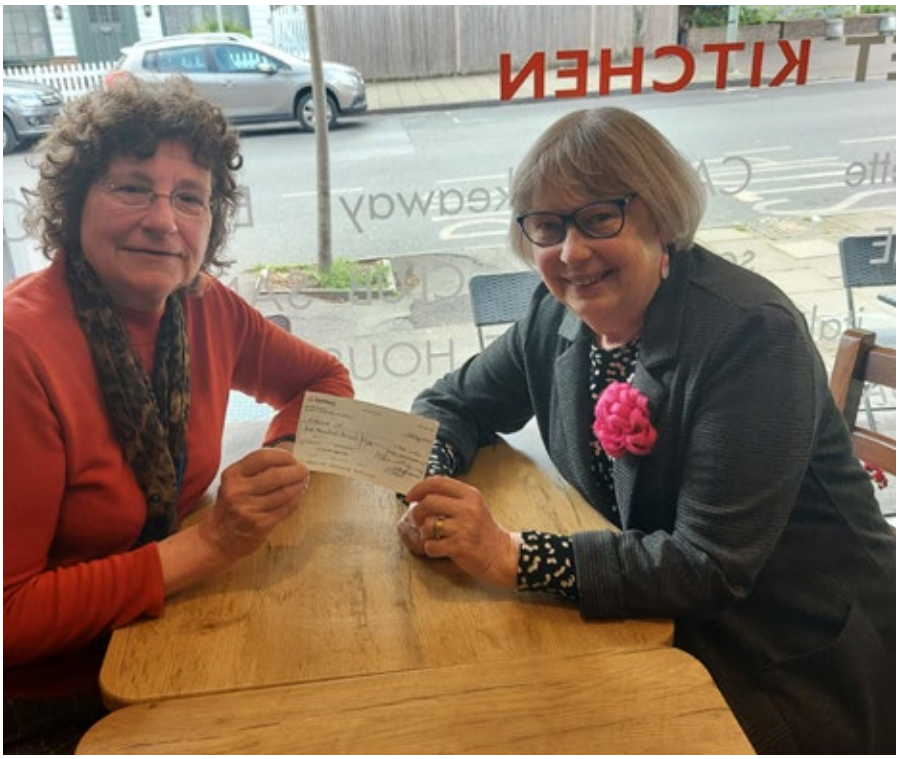
Worthing Support Group

Worthing group now has 15 members and is meeting at a local community centre every two months. Its WhatsApp group is proving to be a very useful addition in between meetings.

Now that they have their meeting space organised they hope to invite speakers from time to time.

Oxford Support Group

The new Oxford group will have their first meeting in September at the Nuffield Orthopaedic Centre. It will be run by rheumatologist Shirish Dubey and his team.



Penny Denby (R) receiving donation from Lions President, Jill Thomas (L)

Orpington Support Group

Ten members of the support group enjoyed a leisurely lunch in a local pub in April organised by members Joy and Nina.

Also in April, supported by their local Lions Club, members held a fundraising event at Coolings Garden Centre in nearby Knockholt. Fifty members, friends and supporters attended an excellent guided tour of the nursery before enjoying an afternoon tea together. Jill Thomas, President of the club, handed over a cheque for £500 to the group.

Bromley has the largest population of older people of all the London boroughs (60,100 older people in 2020 set to increase to 82,500 by 2035 (37% increase)) and so a second group could be a real benefit. Some of the funds from the Lions Club donation will be used to raise awareness of PMRGCAuk and the benefits local support groups offer.

The group was also pleased to report the good news that it had been told that ultrasound is at last being used in all cases of suspected GCA. Scans take place at Kings College Hospital, Denmark Hill.

Pinner/Ruislip Support Groups

The Pinner/Ruislip Group has continued to meet monthly although now it is two separate groups that meet monthly, alternating between Pinner and Ruislip.

People are still being cautious about meeting but numbers are slowly creeping up. The Pinner Group had a very interesting talk in May about the importance of exercise and moving, however limited that can be for some. They discussed how important it was to find the right activity that suited the individual's needs and that they would find enjoyable.

They shared tips and ideas about exercise, including local facilities and nice places to walk – with cafes of course – and discussed what stopped them exercising, eg fatigue and habit were common factors within the group. The notes from the meeting were sent to all the members and resulted in some very positive feedback.

Yorkshire Support Group

It has been quiet the last couple of months for the Yorkshire group. The Jubilee celebrations were a focus for a lot of people celebrating in their own community. Members of the group attended the PMRGCAuk Week webinars and gathered lots of interesting and useful information which they were able to share with the rest of the group. This filled a nice gap as they hadn't been able to meet face to face for a little while.

By the time NewsWire is printed, they will have had another Zoom at the end of June and a coffee and catch up in Ilkley in August. A speaker (a physiotherapist) is planned for September in Leeds. They are looking forward to more one-to-one contact as life gets back to a new normal.

Coventry Support Group

The Coventry Support Group had their first face-to-face meet up since the pandemic. Of the ten remaining members, five were able to attend. They shared their lockdown experiences and really enjoyed the opportunity to see each other again after all this time. They discussed what might be happening to all the local newly diagnosed patients with PMR or GCA but couldn't come up with a way to advertise to them satisfactorily, given their other commitments and varying states of health. Overall, they left with a sense of gratitude that life is returning to some kind of normality and plan to meet again in September.

Spotlight on

Group Organiser: Anne Smedley
Group Name: Whitstable Support Group

Condition: I have had PMR for five and a half years and GCA for nearly two years.

How many people typically attend meetings? We are a small group, less than ten members, and we have bonded really well.

How often do you meet? We meet once a month at the Riverside Vineyard Church. It's an amazing modern building with the opportunity to hold a casual or a private meeting, depending on what we need. There's also a lovely cafe. We are very lucky to be able to use this space.

What is the format of the meetings? I try to alternate speaker meetings with casual ones and make sure we go 'round the table' so each person has a chance to tell their story/news. I am a classically trained dancer and have been teaching ballet and adult keep fit for a long time, even in lockdown, where I taught outside. Part of my career involved teaching both wheelchair users, and blind and disabled people so I have been able to offer 'seated exercises' to our meetings which has been popular.

The meetings work well and are a great benefit to members as they are able to share their experiences and relax in likeminded company.

Why did you decide to set up a group? I offered to take on the task when Neelam Russell, the Kent Regional Organiser, called an open meeting and asked for help – she's a great support.

How much time does it take? Just a few hours each month plus the meeting.

Does anyone else help you? There is a lovely lady, who I collect en route to the meeting, and she takes care of the 'money tin' and attendance list for us.

If you'd like to join the Whitstable Support Group, please email whitstable@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

PMRGCAuk WEEK

We were delighted to welcome our three guest speakers during PMRGCAuk Week in early June: Sarah Leyland, osteoporosis specialist nurse and clinical advisor to the Royal Osteoporosis Society; Dr Chetan Mukhtyar, consultant rheumatologist from Norfolk and Norwich University Hospital, and Dr Sara Muller, trustee and senior lecturer at Keele University.

Many members and non-members attended or requested the recordings of the webinars to be sent to them, and we have received a lot of very positive feedback from the events. If you aren't able to access the internet or would like a refresher on what was said, please read on for the reports of each speaker.

Sarah Leyland – Osteoporosis, steroids and PMR

Sarah Leyland gave a detailed explanation of what osteoporosis is, its symptoms and causes, the impact of steroids and what patients can do to help themselves.

Osteoporosis is a medical condition where bones lose strength and break more easily. Broken bones, sometimes called fragility fractures, can occur anywhere in the body including in the spine; they are sometimes called vertebral fractures. These fractures can cause longer term problems like height loss, curvature of the spine and ongoing pain. Osteoporosis is a term that is used as a "diagnosis" if you have a bone density scan and your bone density is much lower than the average adult. Bone health is really important. Bones hold us up, help us move and protect our organs; they are where blood cells are produced and they store certain minerals which are important for our health.

Bones have a hard outer shell and inside have a scaffolding structure of bone giving them strength without heaviness. The bone is a living skeleton where certain cells are constantly working, replenishing and renewing the bone. In osteoporosis, this gets out of balance and as a result we get thinning of the bone. Gradually the outer shell and the struts inside get thinner and finally they can break down, the bone loses its strength and it breaks more easily. The most common sites to be affected are the wrist, spine and the top of the thigh bone (hip fracture). Broken bones with osteoporosis heal in time, but as these fractures tend to mainly affect older people, they don't always heal so well or so quickly. We know 1:2 women and 1:5 men over the age of 50 get a broken bone due to poor bone health and/or osteoporosis.

There are other risk factors to osteoporosis and fractures. About 80% of our bone strength is to do with our genes, and race: for example bones of Afro-Caribbean people are bigger and stronger to start with. Women live longer than men and start with smaller bones which will get weaker with menopause, and so are at greater risk. Previous fragility fractures also increase the risk of another. These are things you can't change but there are some things you can: your body weight, mobility, smoking, alcohol consumption (excessive amounts) and falling over. Exercise helps to promote the normal bone turnover so being immobile is not good for bones.

Corticosteroids, like prednisolone, affect bone remodelling. They reduce calcium absorption from the gut and increase calcium lost in urine. They also increase the chance of a fracture, but bone density isn't the whole story. Something about steroids affects the structure of the bone (the inside quality of the bone) and makes bone weakness and the risk of a fracture more likely. Bone strength is lost most in the early months of starting on steroids and higher doses (7.5mg or more) are of concern. Fortunately, bone strength improves when steroids are stopped (don't stop without discussion with your doctor).

There are no perfect tests to know if bones have lost strength or have osteoporosis, but bone density can be measured though a DEXA (dual energy X-ray absorptiometry) bone density scan. The lower your bone density compared to the average adult, the more likely it is that you have osteoporosis. You will usually have a DEXA scan as part of a Fracture Risk Assessment (FRAX is a computer-based tool). This is when they look at other factors that may suggest you have weaker bones, eg old age, other medications, body weight, family history or medical conditions and they will be able to work out the possibility of fracture risk in the next 10 years – this helps determine whether you need drug treatment to strengthen your bones.

Medications for osteoporosis are bisphosphonates such as alendronic acid (tablet) and zolendronic acid (drip) and they are generally given to people who have high fracture risks: usually in those over 50 years old. They may sometimes be given to younger people on high dose steroids or who have had a previous fracture. A hospital specialist will advise on this.

Bones need to be kept strong and need feeding. They need a healthy balanced diet: calcium rich, protein, complex carbs and fruit and veg. It is difficult for people restricted by PMR but ideally bones need exercise: weight-bearing exercises, standing exercises with a bit of effort or push behind it – e.g. stamping or jogging; muscle resistant exercises – tricky with issues with your muscles. But the principle is that using your bones is beneficial. Balance and muscle strength exercises help to prevent falls and possible fractures. Just a small amount for example, standing for a bit rather than sitting, is helpful.

If you are unfortunate enough to have painful osteoporotic fractures, particularly in the spine there are many approaches to help with this pain. There is lots of information on this and other topics covered by Sarah on the ROS website **www.theros.org.uk**

Dr Chetan Mukhtyar – GCA: A Giant Update

Our second webinar was from Dr Chetan Mukhtyar who spoke in depth about GCA, explaining what it actually is and the range of symptoms someone might experience as well as the treatment and care they should expect.

What is GCA?

GCA is a spontaneous inflammation of large blood vessels. Large blood vessels are defined as any vessel which is outside of an organ. They have three different layers, the innermost layer (the intima); the outer layer (the adventitia); and the middle one (the media). They are living tissue and need blood and oxygen. The intima gets what it needs from the lumen (blood) but the surrounding layers, the media and the adventitia, need their own blood supply and so there are tiny blood vessels within those layers. Occasionally you have 'bad' cells that leak out and enter the adventitia and these bad cells can slowly make their way into the media, breaking down all the barriers in between, and the cells come together in what we call a giant cell and cause the intima to swell up and the blood flow to slow down.

The large blood vessels that get affected are the arch of the aorta, which is the main blood vessel coming out of the heart, and the arteries that go into the head (carotid artery) and the arms (subclavian artery). Some people are affected in either or both of these arteries. The arch of the aorta can also get affected in some people.

What does arteritis actually mean?

When an artery becomes inflamed you start to get swelling and that means that there is less space for the blood to flow through and there's decreased blood flow. If inflammation continues, the bit of the body that blood was flowing to, no longer receives as much blood. This causes symptoms which will vary depending on where is affected.

If the temporal artery is affected, there could be tenderness at the side, top or back of the head. The artery that goes to the ear might cause pain around the ear. Deeper arteries in the head can be involved which can cause a severe headache; arteries that go to the teeth can cause a toothache and the artery that feeds the eye can cause double vision. The artery that supplies the muscles around the jaw will cause pain when chewing. Arteries that supply the muscles that help you swallow may experience pain when swallowing. Arteries that supply the voice box may cause a hoarse voice.

In the subclavian circulation, arteries go to the back of the neck, to the shoulder and the arm. Inflammation here causes stiffness in the neck and arm.

Symptoms of absent blood flow

If the blood vessel gets completely blocked, the tissue will be affected. A blocked blood vessel going to the back of the eye results in loss of vision. If the blood vessel going to the back of the brain becomes blocked, a stroke can occur. If it's the blood vessel going to the eardrum or the tongue, you suddenly lose hearing or the tongue stops working properly. Thankfully these two tissues are capable of regeneration so they can return to normal, but nerves or neurological tissue can not reverse eg stroke and eyesight.

Frequency of eye symptoms

From studying 350 patients consecutively diagnosed at Norfolk and Norwich University hospital over the last 10 years, Chetan and this team found 101 (29%) had some symptom of eye disease and nearly 50 patients (13%) had visual

loss – five of whom had bilateral loss – mostly caused by diagnostic delay. Six people (2%) had visual loss with no other symptoms ie sadly, there was no warning.

How common is GCA?

There are 22 cases per 10,000 per year above the age of 50 with an increased prevalence in the east of England which is attributed to a Viking/Scandinavian genetic makeup. It peaks in the 8th decade, ie during the 70s, and unfortunately, like a lot of autoimmune diseases, it affects women more.

If you have symptoms what should happen next?

There is a lot of discrepancy throughout the country on what happens to someone with GCA. There is work underway to create standards of care throughout the UK, but this will take time[1].

At the moment, in Norwich, if someone is identified as potentially having GCA whether through primary care, A&E or another department, they ask, is the eye involved or not? If yes, they need to go to the eye clinic on the same day. If it is not involved they are referred, the same day, to the on-call rheumatology doctor. If they suspect GCA they must do the relevant tests, eg blood tests, before prescribing them steroids, and within seven days Chetan will ultrasound scan them.

If the scan is positive, GCA is diagnosed. If the scan is negative or equivocal, then the overall symptoms and test results are considered and either an alternative diagnosis may be made or another test – biopsy or PET scan – is undertaken.

Once diagnosed, the three drug options (depending on circumstances) currently are prednisolone, methotrexate and tocilizumab.

A patient needs a definite diagnosis, proven by biopsy or imaging, and a plan for prednisolone. They should expect an education appointment with a specialist nurse, a follow-up appointment, a helpline number in case of relapse, and monitoring for complications (diabetes, blood pressure, osteoporosis).

Patients should not change their dose because they think they might be having a relapse – these also need to be diagnosed objectively – they should exercise and eat healthily, bring their documentation to appointments (steroid plans and letters), attend appointments and blood tests, and have their vaccines.

1 This work is being undertaken by a group of rheumatology and ophthalmology clinicians from across the country with PMRGCAuk involvement.

Dr Sara Muller – Long-term use of glucocorticoids for PMR

We rounded off the series of webinars with an excellent talk from Dr Sara Muller on the follow-up of a PMR Cohort Study undertaken at Keele University.

Sara talked about how, when they are diagnosed with PMR, most people are told that they will need to take steroids for about two years. In the last few years, there have been studies in the USA and the UK that suggested this might not be true for a large proportion of people and that they might need treatment for much longer.

The study from America suggests that half of people stopped taking steroids after six years (**Comparable rates of glucocorticoid-associated adverse events in patients with polymyalgia rheumatica and comorbidities in the general population – Shbeeb – 2018 – Arthritis Care & Research – Wiley Online Library**). The UK study said half stopped after 20 months, but a quarter were still taking steroids after four years (**Incidence, prevalence and treatment burden of polymyalgia rheumatica in the UK over two decades: a population-based study | Annals of the Rheumatic Diseases (bmj.com)**).

Sara explained how, at Keele University, they were running a study where they had sent people regular questionnaires for two years (at the time they thought that would be long enough) after they were diagnosed with PMR. In 2017 they were able to get funding from Versus Arthritis to follow them up again, an average of five years after their diagnosis. Keele wanted to know how many people were still taking steroids and whether they could tell at the time of diagnosis, or soon after, who would need steroids for longer.

Keele sent out 287 questionnaires and 197 people responded. A few people said they had never taken steroids. In the people who said they had used steroids, four in every ten reported that they were still taking them. The average dose they were taking was 5mg a day.

There was no difference in the maximum dose of steroids people had taken, and no difference in the pain and stiffness symptoms people reported at the time of diagnosis or soon after, between those still taking steroids at five years and those people who had stopped. The only differences the researchers could see were that people still taking steroids were slightly older at diagnosis (73 versus 70 years) and that 39% of them reported changing their steroid dose by themselves compared to 11% in those who had stopped taking steroids. We don't know whether the longer treatment is because people changed dose without their doctor's advice or if they changed their dose because they had been taking steroids so long.

The other thing that Keele were able to see, was that still taking steroids was related to the pattern of how severe people's pain and stiffness were over the first two years of their PMR. (The researchers published another paper on

these patterns. **Longitudinal clusters of pain and stiffness in polymyalgia rheumatica: 2-year results from the PMR Cohort Study | Rheumatology | Oxford Academic (oup.com).**) Perhaps unsurprisingly, people who had longer lasting pain and stiffness in the first two years were more likely to still be taking steroids. What was more surprising was that in the group of people who recovered quickly from their PMR symptoms and seemed to stay well (those people whose PMR symptoms over time looked like we often describe), one in four were still taking steroids after five years.

While it would have been helpful to be able to predict who might need steroids for longer, the researchers couldn't do this in this study. They think this study means that everyone needs more regular monitoring by their health care team, especially to prevent steroid complications.

The good thing about this study is that people were invited into the study from GP practices, so it includes everyone, whether or not they saw a rheumatologist. However, some people in the study might not have what a rheumatologist would think was PMR. This might not matter though if we are interested in improving care for people who are diagnosed and treated with steroids as though they do have PMR.

You can read more about it here if you like: **Long-term use of glucocorticoids for polymyalgia rheumatica: follow-up of the PMR Cohort Study - PMC (nih.gov).**

Thank you to all our members who gave donations for PMRGCAuk Week and for the lovely messages of thanks.

Squirrel by Jill Jopson

Crocuses by John Minter

Notelets now available!

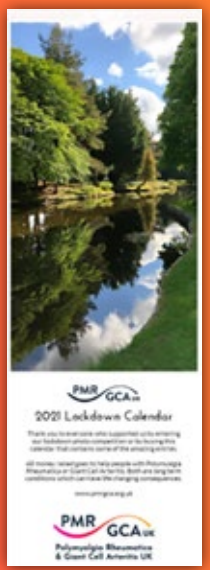
We launched the new PMRGCAuk notelets during PMRGCAuk Week. They have been produced from two of the images submitted during the previous two photo competitions. Squirrel by Jill Jopson and Crocus by John Minter - both are available to buy in packs of 10 for £6.95 plus p&p. Aside from being lovely designs, the reverse of the card raises awareness of PMR and GCA and is a really nice way to spread the message about the conditions as well as help us to raise funds.

If you'd like to buy a pack or two, please email **cards@pmrgca.org.uk**

Photo competition

We also launched the 2022 photo competition to find images for our 2023 calendar. The calendars proved so popular last year, selling out within days! Once again, we are looking forward to seeing the images that you send through. Hopefully as more of you will be travelling and out and about this summer there will be even more opportunity for photography. Photos can be taken with a digital camera or phone, but do make sure the images are greater than 500kb. By entering, you give your consent for your photo and name to be published on the calendar, in NewsWire and on social media.

Please send in your entries to **cards@pmrgca.org.uk** by 29th August 2022.



Members' corner

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

YOUR STORY:

PMR, DIABETES AND WEIGHT LOSS

Jane (69) from Shropshire, shares her experience with us.

The first indication that I had PMR was when my legs gave way in December 2016. I was visiting Berlin for the Christmas markets, but spent the whole three days in the hotel room as I couldn't walk or get up from sitting, and my back ached. My GP thought it was PMR, and I was diagnosed in March 2017. My starting dose was 15mg and this worked really quickly – I felt much better by the next morning – and I stayed on this dose for four weeks.

In June 2017, I was diagnosed with diabetes and put on the diabetes drug, gliclazide. I weighed 12 stone. I wanted to do everything I could to help lose weight and improve my diabetes which I learnt could be negatively impacted by the steroids I needed for PMR. I had read on the HealthUnlocked forum about following a low carbohydrate diet to lose weight, so decided to try that.

I had my next diabetic review in December 2018 and I was advised to come off the diabetes medication as my hba1c (blood test that measures the amount of glucose in the blood) was now out of the diabetic or pre-diabetic range.

Earlier in 2017, while I was waiting for the PMR diagnosis I had struggled to get up and down the stairs, and had stayed in bed a lot, with my husband cooking ready meals and buying me chocolates to make me feel better! As soon as I had the diagnosis, and prednisolone had helped me to feel better, I was able to cook for myself and go shopping. I read all the nutrition labels and ate carefully. As well as going into diabetic remission I lost a lot of weight – over three stone in around six months.

I am lucky that I enjoy salads and I am happy to eat them all year round. I don't eat vegetables that grow below ground, instead sticking to above ground veg. For dessert, I eat berries with Greek yogurt. I made my own keto bread with almond flour but now eat a loaf called Hilo (which is lower in carbohydrate and higher in protein than regular bread). I bought the small book Carbs and Cals Pocket Counter from Diabetes UK and that helps me to check foods.

I was 63 years old when I developed PMR and, fortunately, I was otherwise well and mobile. This meant I could walk, which is something I have always enjoyed. I bought a Fitbit and built my walking up until I was able to walk a lot. My aim, even now, is to walk 13,000 steps a day and I do so most days. This helps my bone density, my weight and also my diabetes. I have been in remission from diabetes for over four years although I still consider myself type 2 diabetic.

I still have PMR. Last year I tapered down to 4mg of prednisolone but then had a flare which saw me increase the dose to 9mg. This time I'm tapering more slowly and am currently at 7.5mg. Aside from that and a few aches, I feel fitter than ever.

Jane's user name on the HealthUnlocked forum is **KoalaJane** (**https://healthunlocked.com/pmrgcauk**)

www.diabetes.org.uk

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.

Dr Sarah Mackie
Consultant Rheumatologist

A Rheumatologist Explains...

Barbara from the Midlands wrote to ask if there was any particular diet that she should be following now that she is prescribed steroids for PMR.

Dear Barbara,

The benefits of a healthy diet are real, but accumulate over years of healthy eating; there is no quick-fix. In general, eating a varied diet with lots of wholefoods is far healthier than restrictive diets involving cutting things out (or worse, drastic "crash" diets that starve your body of energy).

We all know that healthy diets have lots of different types of fruit, vegetables, nuts, dairy and lean protein. But we are also all tempted to indulge in processed foods, "treats" and things with added sugar or salt, which make lots of money for the food industry but aren't very good for our health. To make matters worse, steroids can make you feel anxious, depressed, and very hungry. It's totally understandable that dietary quality can take a back seat for a while, but it's never too late to take positive action with your diet. Over time, small changes make a big difference.

As a doctor I quite like this recent article **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9080102/** which comes with a link to a leaflet for patients (see its Supplementary Data link). I summarise it here.

Bones won't tell you they're in trouble until they fracture later in life, so you need to be pro-active about them now. For healthy bones, people taking steroids should aim for 1.0-1.2g of calcium each day; at least 600-800 units of vitamin D daily; and 1-1.5g protein every day per kg (or 2.2lb) of body weight (unless you've been told to restrict protein because of other medical conditions). Dark leafy vegetables, like spinach, are good sources of calcium, as is skimmed milk. Oily fish is a great source of vitamin D; your skin also makes its own vitamin D when you're out in the sun. Protein is found in meat, fish and dairy; getting enough protein can be challenging for vegans, who need to take special care with this.

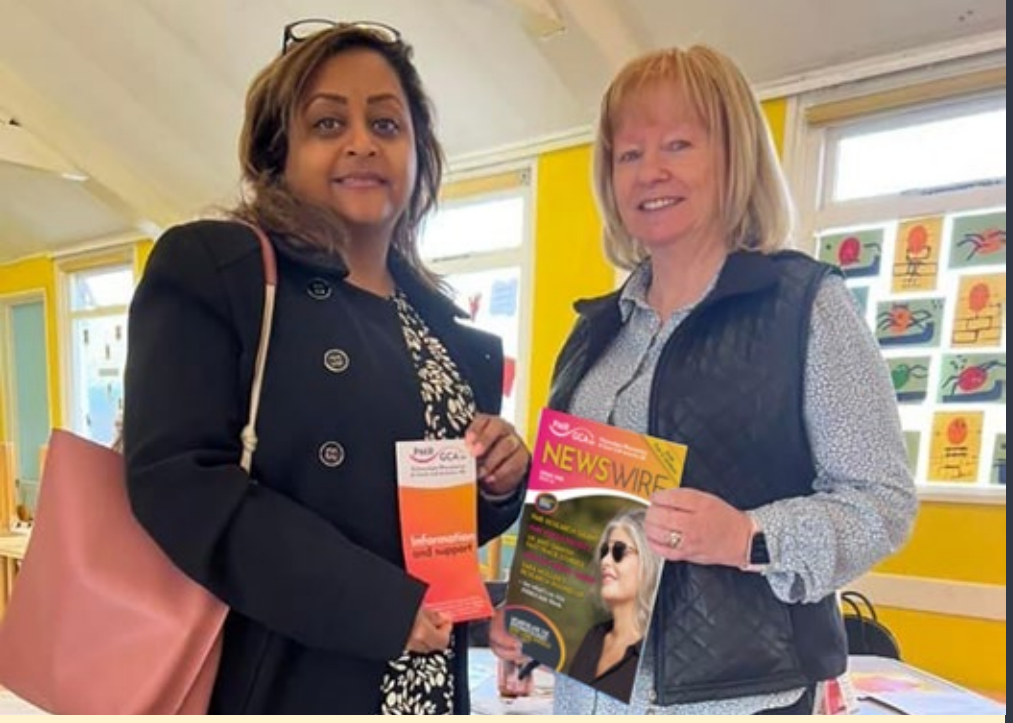
People taking long-term steroids usually put on fat around their middles, and the body finds it harder to deal with sugar. Quite apart from the emotional impact of weight gain and the financial impact of having to buy new clothes, this isn't great for your long-term heart health. However, in practice, focusing too much on fats, "carbs" or calories isn't always helpful as it can lead to quite boring or unhealthy diets. It can be better to simply look at what you eat and plan out meals based around unprocessed, whole foods including lots of fruit and veg.

Be kind to yourself and remember you are still the same wonderful person on the inside, even if you look different since taking steroids. Talk to your own doctor and enlist the support of friends and family; and above all change your diet for positive reasons (improving your long-term health) rather than out of guilt, fear, shame or negativity about your body. And in three words: eat more vegetables.

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.



Raising awareness of PMR and GCA

Trustee Janice Maddock recently gave her first awareness talk since the pandemic. She was invited to speak at a Community Coffee Morning organised by a local church in Wembley back in February. Here she reports on how it went.

"It was a lively affair where people were just starting to feel comfortable venturing out again. Mask-wearing was still visible but there was a buzz of chatter and laughter over lovely refreshments (including the vicar's famous lemon drizzle cake). The atmosphere was so lovely and it felt good to be back talking face to face.

There were 32 attendees and I was introduced to many of the people there including three local councillors.

Halfway through the two-hour session I was invited to speak for a short while on PMR and GCA – signs and symptoms and my experience as a PMR patient. I had leaflets on hand and a copy of Kate Gilbert's book and three people requested my contact details:

- A health professional who had a table with leaflets and information about diabetes. She wanted to invite me to a future 'health day'
- A lady whose neighbour had PMR and is struggling to manage it
- A councillor whose mum had PMR but is now in remission.

Another councillor took a photo and added it to her Facebook page with links to the charity. I had lots of good questions and people seemed very interested in what I had to say.

I gave some 'symptom' leaflets to the vicar who wanted to take them to his Dementia Café and I also offered to go and talk there at a later date.

It was so nice to resume my awareness talks especially in such a friendly and informal environment and hope this leads to more opportunities in the future."

In memory of Professor Justin Mason

We were deeply saddened to hear of the sudden death of Professor Justin Mason in May.

Many members will remember the talk he gave on PMR at last year's AGM which was praised for its quality and clarity.

Humphrey Hodgson, chair of PMRGCAuk, remembers him from when they both worked at the Hammersmith Hospital over 20 years ago, and saw him beginning to develop his career as an academic researcher into the problems of vasculitis. He spent his career working on both basic science problems in these diseases and clinical aspects. He held prestigious posts at Imperial College, the Kennedy Institute of Rheumatology, and the National Heart and Lung Institute. Humphrey said, "I met him again when, years later, PMRGCAuk wanted to lobby the Department of Health, and we needed a rheumatologist to help us. We asked Justin. He immediately and gladly agreed to come to talk to the Director of NHS England, and eloquently (and successfully) argued for a new initiative from the Department. He was extremely talented and this is a huge loss."

Former trustee Dr Chetan Mukhtyar paid tribute to him in his recent webinar: "Justin was a leading light in the world of large vessel vasculitis and had been a supporter of PMRGCAuk throughout his career. He was the gentlest, kindest soul who passed away before his time leaving behind a very strong legacy of research that we should all carry on."

Our thoughts are with his family, friends and colleagues.

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

Notes from the Chair – Richard Cuthbert

June 2022

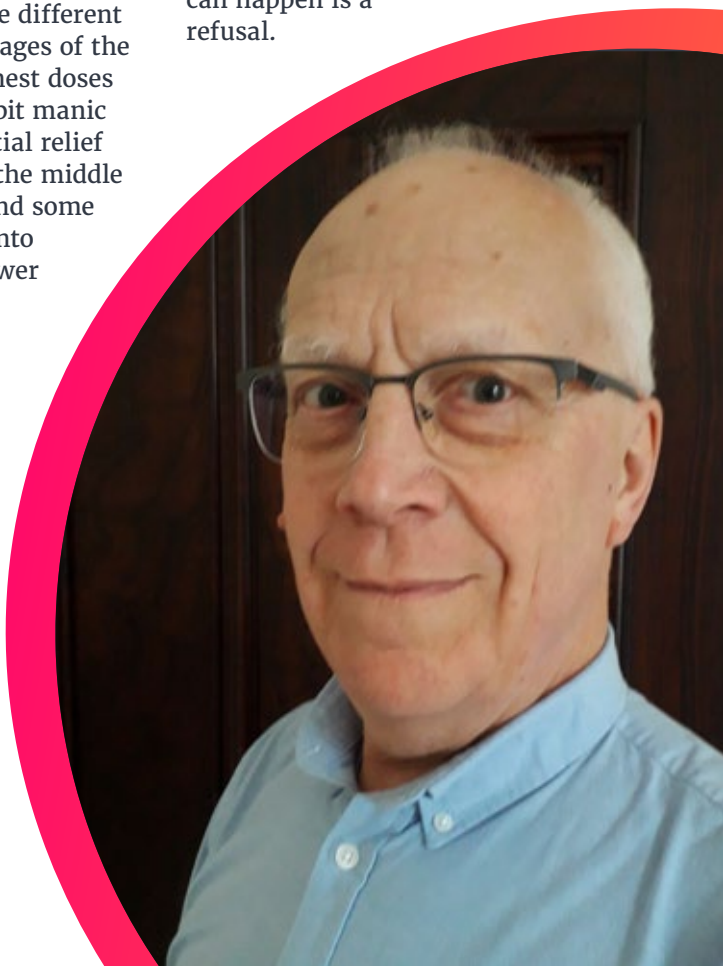
Back in March we held our AGM online and we hope fervently that we will be gathering again in person from next year. We were delighted to be joined by Dr Sarah Mackie who gave a presentation on "Progress in PMR" which was well received and led to some very relevant questions. It is easy to forget how lucky we are here in the UK to have good access to world-renowned experts who are also so concise and approachable – thanks again, Sarah. The business agenda passed smoothly with the most important aspect being the resolutions to permit the transfer of the charity's assets and activity to a more modern vehicle.

The new entity is a SCIO (Scottish Charitable Incorporated Organisation) called PMR-GCA Scotland. Our activities and membership base will remain the same but we will enjoy limited liability status similar to the UK charity. The formal transfer can only be done in a practical sense when we have opened a new bank account for the new entity. Many of you will know how that can be an extremely protracted process.

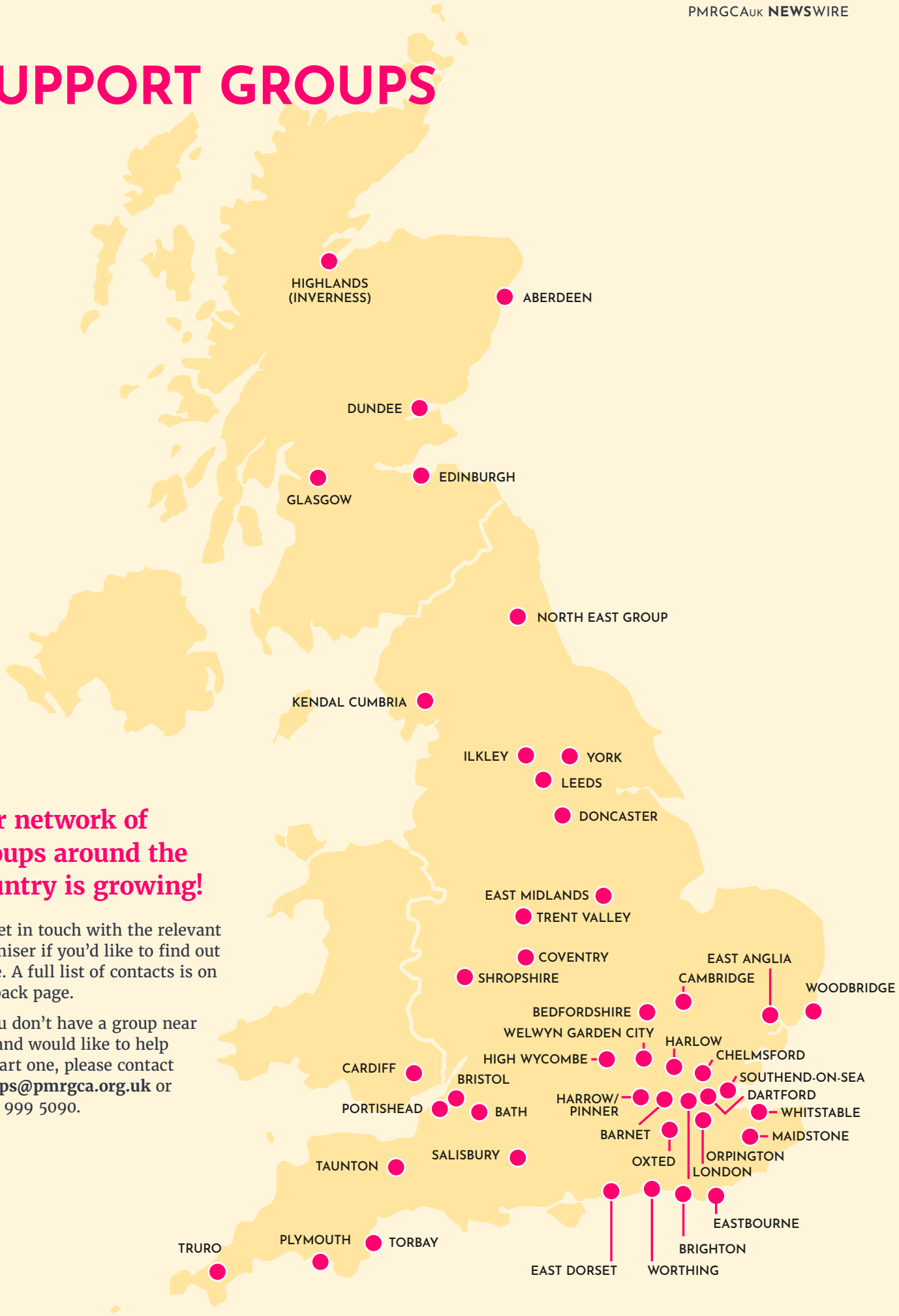
Work continues on trying to establish a new support group in South West Scotland. We held an introductory meeting online which went well, but it also highlighted some of the difficulties in trying to be active in more rural communities which are the very places that can have difficulty accessing things like a support group. One lady said in advance that she might have difficulty getting any internet connection on the day and she ended up with a connection through a dongle. This generated picture and sound freezes so she had to drop the video element to allow any semblance of a usable sound connection. That is not satisfactory in light of our Scottish Government's commitment to rolling out adequate broadband throughout the country. I praised some parliamentary activity in the last issue, but I must call out this situation – it's really not acceptable.

I am writing this paragraph whilst on holiday in France – such is the dedication required to meet deadlines. It is of course delightful to be away, particularly after postponing this trip in 2020 and again in 2021. Patients reading this, however, know how difficult holidays can be when you also need to take your PMR/GCA with you. There are different problems at different stages of the conditions – at the highest doses of steroid you can be a bit manic in enjoyment of the initial relief of pain, there are then the middle doses when brain fog and some aches and pains come into play, followed by the lower doses which is where I am just now with my GCA. At 4.5mg I am relatively pain free but the biggest issue that can spoil the holiday is the fatigue.

Many of you know what I am talking about – how it is sometimes impossible to keep your eyes open during the afternoon. It is only human nature to want to maximise one's own holiday enjoyment, but it is also important that we try to give the best holiday possible to spouses and partners who might spend the rest of the year making constant allowances for our PMR/GCA. I have had help in years gone by from a consultant who was reluctant to allow a short-term increase in my daily dose of prednisolone, but was willing to let me have a steroid injection which was administered by my GP or a rheumatology nurse. These worked very well in terms of a physical and mental boost, and the beneficial effect lasted for two to three weeks. I would totally recommend a pre-holiday chat with your medical advisers to see if this might be appropriate for you – the worst that can happen is a refusal.



SUPPORT GROUPS



Our network of groups around the country is growing!

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.

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.

SUPPORT GROUP CONTACTS

Our network of groups around the country is growing!

SCOTLAND (Scotland is an independent organisation)

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