PMR GCA UK
Polymyalgia Rheumatica & Giant Cell Arteritis UK

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NEWSWIRE

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ISSUE 35

Highlights from PMRGCAuk AGM and Members' Day...

PMR AND GCA ARE WE MAKING PROGRESS?

TAPERING STEROIDS

THE NURSING PERSPECTIVE OF MANAGING PATIENTS WITH PMR AND GCA

FACTS AND FIGURES OF OUR HELPLINE

DR SARAH MACKIE TALKS ABOUT THE EFFECTS OF PMR ON EXERCISE

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Welcome

It is hard to believe that we are drawing to the close of another year where Covid-19 has dominated our lives. While we have been relieved that lockdown rules have relaxed, vaccines and boosters have been and continue to be administered, it isn't a surprise that our helpline has been busier than ever.

It is a great source of satisfaction to know that we can be at the end of a phone for many people. With the difficulties many have faced getting appointments with doctors and consultants, our helpline volunteers have been able to support patients who were struggling and often in need of some quite basic information. Having someone knowledgeable to talk to has eased callers' concerns and enabled many to understand their condition better. The detailed report on the helpline is a fascinating read.

It was lovely to see so many of our members turn up to support our AGM and Members' Day and to listen to the speakers we had lined up. They were all excellent and I recommend that you read all the reports of their talks either to catch up on what was said or as a refresher of the day.

While many of our members are still cautious about meeting up and are still benefiting from Zoom support group meetings or email catch ups, it has also been encouraging to read how some of our support groups are now meeting face to face and relishing the benefits of social contact.

I hope you have felt supported by PMRGCAuk throughout this difficult year whether by reading NewsWire, attending a support group, logging on to our online forum on HealthUnlocked or by talking to someone on our helpline. I also thank you wholeheartedly for your support, whether that's through being a member, making a donation or volunteering.

Finally, wishing you all a happy Christmas and a new year that brings improved health and hopefully a bit more certainty to our lives.

Humphrey Hodgson

Humphrey Hodgson
Chair of Trustees

PMRGCAuk Christmas opening hours

The office will be closed from 5pm on Friday 17th December until 9am on Monday 3rd January 2022.

The helpline will be available every weekday from 9am to 5pm. A voicemail service will take messages outside of normal hours – please do leave your name and contact number if you would like someone to return your call.

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.

In this issue, I'm going to focus on a single study – a systematic review and meta-analysis. This is a careful search of all the published papers on a topic and a statistical summary of their findings.

The questions in this case were:

1. how long people need to take steroids for PMR; and
2. who is likely to need steroids for a longer time?

The authors found 2,863 published articles that might have been relevant. By reading through the titles and then the abstracts (short summaries that are published with the paper), they were able to reduce this to 21 papers that contained useful information. They then assessed how good these papers were using a "quality appraisal" checklist for cohort studies (that is studies that follow people over time without changing treatments that people are given). They found them all to be of moderate to high quality.

The studies they found were all quite different and the authors noted problems with defining important aspects of the disease, such as relapses and flares. Only studies looking at people with PMR without inflammatory arthritis or giant cell arteritis were included.

The authors found that, on average, 77% of people were still taking steroids one year after their diagnosis, 51% after two years and 25% after five years. This contrasts with the guidelines that suggest that steroid treatment should have finished in less than two years. There was no information to suggest that the length of time on steroid treatment is changing over time.

The EULAR/ACR guidelines say that people who are at risk of needing steroids for longer should be referred to a specialist. So, the authors tried to work out who those people were. They found data about age, gender, starting dose of steroids, peripheral arthritis (arthritis that is not in the spine), inflammatory markers (eg ESR, CRP) and use of the drug methotrexate. However, these data did not show any links between these factors and the length of time people were on steroids. What the authors did not discuss is that some of these things might be quite circular. For example, people who were given methotrexate might have had to take steroids for even longer without the methotrexate. We do not know why they were given it and the designs of the studies included didn't allow this to be considered.

Although this isn't the most rigorous systematic review, I think it does highlight two important points. 1) People with PMR take steroids for longer than guidelines suggest. 2) We do not know who is at risk for needing treatment for longer, so referring the correct people is very difficult.

These things might not be very surprising, but it is important that we have evidence to show this is the case. Then we can start to try to do something about it.

Floris, A., Piga, M., Chessa, E. et al. Long-term glucocorticoid treatment and high relapse rate remain unresolved issues in the real-life management of polymyalgia rheumatica: a systematic literature review and meta-analysis. Clin Rheumatol (2021). https://doi.org/10.1007/s10067-021-05819-z

Research updates on our website

Each month, we also post a review of a recent piece of research. We include an explanation of the purpose and result of each study and a link to the relevant paper (if there is one). You can find this at **https://pmrgca.org.uk/professionals/medical-research/**

Groups around

Truro Support Group

A few of our members have joined Zoom meetings with Taunton and Plymouth groups run by Wendy Morrison, South West Coordinator. We've had no face-to-face meetings owing to Covid, although four of us were invited to a private cream-tea at the house of one of our members. This was in a large, airy conservatory with all windows open and all precautions taken. We aim to re-start our monthly meetings at the Truro Golf Club in November.

Harrow and Pinner Support Group

The Harrow and Pinner Group met once again at an outside café on a lovely, sunny August day. There were six of us and we discussed meeting again in our regular hall. We then devised a policy together to ensure everyone would feel safe. Nine of us finally met face to face in September at our usual venue. We spent time reconnecting with each other and discussing personal experiences and updating on all things PMR and GCA. We decided not to offer refreshments but will be reviewing that in the future. I had excellent feedback about the meeting and I am looking forward to our next meeting in November.

Yorkshire, Leeds and Ilkley Support Group

Our group members have been busy meeting up with family and friends and going away on day trips and holidays since July and so we decided to meet on Zoom in October. We kept up to date on activities or new information by email during this quiet time.

We are planning our first face-to-face group meeting in almost two years! This is at the John Lewis Community Hub in Leeds and we have eight people so far interested in attending. Also one of our members has kindly volunteered to meet up for an informal chat and coffee for anyone in the Kendal area. There are some who can't travel or don't yet feel it is time to meet up in a public place due to where they are in their PMR/GCA journey and they will be happy to continue on Zoom.

Trent Valley Support Group

The Trent Valley group had a second face-to-face meeting on 8th September at a very nice waterfront pub/restaurant, where they were happy to accommodate us for coffee, with five members plus my husband. We have also recently had a new member join, who because she had a rather uncommon surname I remembered from college 45 years ago but who I had lost touch with. We only live about six miles from each other, so although unfortunately it's because we both have PMR, it has been a lovely reunion.

Kent Regional Update

We are delighted to let you know that there has been lots happening throughout Kent. Some support groups have, understandably, been taking things slowly as we open up after the pandemic. Others, for example, **Whitstable**, have been able to meet up in person. We held a meeting to re-start this group, and welcomed 10 members in person in late June. We have a new group organiser, Anne Smedley, who has already arranged several meetups including a very successful webinar. Whitstable has also arranged a Christmas lunch for early December.

Maidstone Support Group have kept in touch via monthly emails and phone calls since Covid began. We have shared problems related to PMR and GCA and also family news, knitted chocolate orange covers for a Christmas family get together and passed on tadpoles in exchange for plant cuttings!

Orpington Support Group have restarted their meetings in person and enjoyed a reunion after many months of being unable to meet face to face. We welcomed a new member who developed GCA during the pandemic, which had been a difficult experience for them. We also continue our Zoom meetings on the fourth Wednesday of the month and this is open to any charity member who doesn't have a local group and would like to join in. Please email **orpington@pmrgca.org.uk** for more information.

We are now very close to launching two new support groups. We have found a new group organiser and a venue for the **Dartford Support Group**, covering Bexley, Dartford and Gravesend, and plan to hold our first meeting imminently. The Southborough Support Group for members living in Sevenoaks, Tonbridge and Tunbridge Wells will hold its first meeting on 25th January at 10.30am. Any members who would like more information on these groups or to help with the set-ups are welcome to contact me on **kentro@pmrgca.org.uk** and as always, all members are most welcome to attend any of our group meetings in Kent, regardless of where they are located. Any thoughts on other locations in Kent for additional support groups are very welcome, please just let me know.

the country

Southend/Chelmsford Support Group

We had our first face-to-face meeting on Monday 4th October with an attendance of 18 including four new members. The meeting went really well and everyone enjoyed getting together again. Professor Dasgupta gave a very interesting and informative talk. We were able to record the meeting and we sent out the link or a CD to our members afterwards. We are hoping now to carry on with face-to-face meetings but will also carry on with Zoom.

Bath Support Group needs support!

Sadly, the Bath group organiser has had to step down for personal reasons and so far there has been no-one able to take over. However there is still a big need for Bath group members to be supported. Wendy Morrison, South West Coordinator and Ros Pearman, a charity member, have agreed to lead the meetings alternately every other month (Covid permitting) but they really need some help to deal with the membership list, sending out emails and arranging venues. If you live in or around Bath, could you or a family member, help Wendy and Ros to keep the group going? Please get in touch with Wendy Morrison at **taunton@pmrgca.org.uk**.

Spotlight on Group Organisers

Group Organiser: Catherine Spencer
Group Name: Brighton Support Group

Condition: I was diagnosed with PMR nine years ago. I had classic symptoms whereby I couldn't turn over in bed and could barely move in the mornings as I was so stiff. This was a challenge as I was a full time class teacher. I came off prednisolone more than three years later but had a relapse after only a couple of months. I started all over again, tapered down to zero over three years before another relapse. I have now been on 2mg daily for more than six months and will continue to stay on this low dosage for a while.

How many people typically attend meetings? About nine people used to attend our meetings in a local pub, where we met at a quiet time in a relatively private alcove. Our Zoom meetings during Covid every other month have had between four and nine people.

Before coronavirus how often did your group meet? We used to meet every two months and have kept this up online during Covid.

What was the format of the meetings? Both before Covid and now on Zoom, we go round updating the group as to how we are, give support and information to anyone who wants it, share current medical thinking on Covid and PMR/GCA and then just chat! We are very supportive of each other.

How has coronavirus changed that? We have not met face to face yet but aim to in November if the group feels it is safe to do so. By then, the most vulnerable in the group should have had booster jabs. We aim to be back in the same pub at our regular table on a quiet Monday. As a group, we have now become good friends with one another, so meeting face to face will be great. We will miss one member who moved to Lancashire.

Why did you decide to set up a group? I was asked to and I'm glad I was. I have really enjoyed getting to know the group better and feel that I am using my own experience to contribute in doing something supportive for others.

How much time does it take? And does anyone else help you? Not too much time at all and I am indebted to Fiona who sets up Zoom for our meetings.

If you'd like to join the Brighton Support Group, please email brighton@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

GCA study to identify vulnerability to sight loss

A team of experts from the Mid and South Essex NHS Foundation Trust and Anglia Ruskin University has commenced a study into a retrospective analysis of signs and symptoms that predispose patients with GCA to sight loss. The results of the study will provide a set of robust criteria for treating GCA in order to prevent sight loss and indicate further avenues for research into causal factors.

The project is conducted by Prisca Gonda, a joint appointee with the MSE and Anglia Ruskin University, supervised at the MSE by Professor Bhaskar Dasgupta and at Anglia Ruskin University by Dr Dan Robbins and Professor Barbara Pierscionek. The results are expected within a year.

As many of you know, giant cell arteritis (GCA), although not common, can have severe consequences if not treated in time, because it can lead to permanent sight loss. The causal factors of GCA are not clear and the disease can lead to such a number of varied symptoms that diagnosis can be difficult. It is particularly important to diagnose GCA early in the onset of the disease and to understand what sort of signs and symptoms may lead to sight loss so that patients can be treated immediately to prevent blindness. We look forward to hearing the results of this study in due course.

Charity News

Trustee takes on expert role for GCA

Our trustee and consultant rheumatologist, **Chetan Mukhtyar**, has been invited, and accepted, the role of UK/European expert adviser on GCA with BMJ Best Practice. BMJ Best Practice is an international resource for clinicians and brings together the latest research and expert input from around the world.

We are very grateful for the support that Chetan gives to our charity and congratulate him on this recognition of his expertise within GCA.

Could you be a trustee?

We have a fantastic group of trustees to support and steer the direction of the charity. However, it would be great to add to and complement the skills of the trustees that we have. If you have a legal, HR, fundraising or journalistic background and would like to help us, or just to find out more about what is involved, please get in touch with **candy@pmrgca.org.uk** We would love to hear from you.

Second payment from Masonic Charitable Foundation

We have received the next instalment of our grant from the Masonic Charitable Foundation. The money is for setting up the befriending project. We are pleased to say that **Neelam Russell** (who is also our Kent Regional Organiser) is also now helping to get the befriending scheme up and running.

Christmas cards and calendars

Our cards and 2022 calendars became available in October. We had two seasonal designs for our cards, and 13 winning images from our summer photo competition were used for the calendar. Cards were available at £4 per pack and calendars at £7.95 each, both plus p&p. Thank you to all the members who submitted images and to the winners in particular. Details of the winners are on page 15.

PMRGCAuk Telephone Helpline

Our helpline is a lifeline for callers when they need help and support. We have six volunteers – from Devon to Doncaster – who answer the phone every weekday from 9am to 5pm. Outside of these hours, callers can leave a voicemail which will be responded to the next day.

Due to a generous grant, the team have had six-weekly training sessions (delivered on Zoom) since 2020. The sessions have helped them become more aware of the need to understand callers' needs and to actively listen while giving support to enable the caller to plan their way forward following the call.

Most callers express their gratitude for being able to speak with someone who understands what it is like to have either condition and to be on steroids in the long term.

It is striking that many callers had not been given much information about PMR or that it is a long-term condition and has a connection with GCA. Callers often think that once the PMR symptoms have disappeared with prednisolone it is resolved.

Many callers had been given a set timetable by their GP to reduce their steroid dose – usually by 1mg a month to 0mg but without monitoring or information that they shouldn't reduce if their symptoms persisted or increased.

It has been common to receive calls where there is difficulty reducing prednisolone by 1mg per month at low levels (5mg – 6mg) and reporting symptoms which sound very similar to low cortisol levels. There seems to be a lack of understanding by some GPs on the very slow tapering of prednisolone at these low levels in patients who have been on long term steroids.

Not all GPs are referring patients with GCA to a rheumatologist and continue to manage them. This is also true for some patients with PMR that is not responding to management with prednisolone.

Some callers have struggled to get a diagnosis of PMR/GCA without having raised inflammatory markers and despite having classic textbook symptoms.

The frustration of many callers about not being able to speak to their GP/consultant during the pandemic lockdowns was very evident, with many being left to self-manage their steroid dose during this time.

Although this information has been sourced from a small sample of people these themes appear to be fairly consistent over the past year and also from our observations of previous years' callers.

We would like to thank Chris Young, trustee and helpline co-ordinator, and the wonderful helpline team who make the helpline possible. Also special thanks to Stephanie Beer who compiles the data and calculates the statistics; the James Tudor Foundation for their grant for training; and to Alice Hanscomb for her expertise and unfailing encouragement during training sessions.

To give you an idea of what they do and who they help, here are some of the statistics from April 2020 to March 2021.

350 calls answered

72% had PMR; **14%** GCA; **14%** had both

The average age of callers was **75** and **2/3** of callers were women

20% were newly diagnosed; **20%** had been diagnosed less than a year; **39%** had been diagnosed between 1 to 4 years and **11%** over 5 years

50% were first time callers and **30%** of all callers called more than once, with a small core who called several times.

55% of callers requested information about PMR and/or GCA and were either sent an information pack or directed to the website for more information

Over half of callers had questions or concerns about prednisolone and/or reducing it

10% of callers asked questions about steroid sparing medications

23% of callers wanted to talk about their symptoms and if they were usual for PMR/GCA, some being distressed or feeling unsupported by their medical team

Between **1%** and **2%** of callers had lost some sight

Just **11%** of all callers were members

AGM AND MEMBERS' DAY

We had a fantastic turn out for our AGM and Members' Day on 4th September. There were 140 members present, with another 40 requesting a copy of the recording afterwards. It was great to see so many of you on Zoom saying hello in the chat and asking questions of our speakers.

The AGM included a report from the chair and treasurer, three trustees resigned and were reappointed, Geoff Holroyd was appointed as treasurer and Janice Maddock was appointed as deputy chair. With the formalities of the AGM completed we welcomed our first speaker, **Professor Justin Mason**, consultant rheumatologist and professor of vascular rheumatology within vascular sciences at Imperial College.

100%

of attendees said said the topics covered by the speakers were very good

PMR and GCA – Are we making progress?

Justin started by explaining the overlap between PMR and GCA. The diseases are often considered in isolation, but one can have cranial GCA, large vessel GCA, PMR or combination of PMR and GCA.

He questioned why we get these diseases. One factor, particularly in GCA studies, has been the influence of genetics. The work does not imply the presence of an abnormal gene, rather a pattern of genes that predisposes one to these conditions. An additional important factor is the likely involvement of a pathogen, perhaps a virus, that initiates these conditions. However, genetics and infection are not the only factor here, because the question remains, why do these diseases particularly pick on those who are over 60? Current research suggests that a decline in the regulatory mechanisms in our immune system is important.

A specific diagnostic test for PMR is lacking and it remains a difficult diagnosis to make and one that often boils down to the response to steroids, which should be pretty rapid on a relatively low starting dose (up to 15mg prednisolone per day). An important requirement and research objective is the development of better blood tests for disease monitoring. The ESR and CRP, while useful and important, lack sensitivity and are occasionally normal when the disease remains active.

If a new patient with PMR is sent for diagnostic scans, which typically they are not, the choices are between ultrasound and PET scanning. These are useful techniques, particularly when the diagnosis is unclear. GCA is perhaps easier to diagnose than PMR because the patient can be offered ultrasound as a non-invasive and rapid diagnostic technique, or a temporal artery biopsy.

There are important challenges that physicians face in the treatment of PMR and GCA. In GCA, we all worry about the potential devastating effect on vision. On the other hand, we have the profound physical impact of corticosteroids. Thus severe, and life-changing side effects of the steroids have to be balanced with the risk of severe and life-changing impacts of the disease.

Steroid-resistant PMR is an important phenomenon. In other words, the patient who is not doing as well on steroids. In this instance, the diagnosis needs to be reconsidered: for example, is the problem actually that the patient has developed an occult (hidden) large vessel vasculitis along with their PMR? This is where the imaging can be so important diagnostically to rule this in or out.

The anti-interleukin-6 drug tocilizumab (TCZ) represents a key treatment advance, particularly in GCA and potentially for PMR in the future. The GiActa trial showed that 56% of patients in a group that received TCZ went into remission, which enabled them to come off steroids after one year. In the second year of the trial, 40% of those patients were able to maintain a long-term steroid free remission. A huge step forward. However, 50% of patients who do well on TCZ will relapse when the drug is withdrawn. The challenge is to work out how to withdraw TCZ safely, persuade NICE and others that some patients will need longer term treatment than one year, and also design and develop other drugs that can offer benefit in addition to TCZ.

Physicians are thinking about how to construct paradigms for the use of different drugs in the treatment of individual patients, so that we have a stepwise procedure to go

through, to maximise efficacy and availability of treatment to patients who need it across the whole of the UK and indeed beyond, while also having strategies to withdraw treatment safely.

The key aims of treatments are to achieve and maintain disease remission; promptly identify and effectively treat patients who are relapsing; but also to minimise the impact of treatment and avoid harm to the patient.

A treatment plan is also needed for new symptoms. A return of the original pattern of symptoms is often indicative of a disease relapse, and the patient should seek medical advice and avoid getting into the habit of putting steroids up and down, as this risks increased side effects. We should all aspire to treatment withdrawal. Patients will generally be on steroids for two to five years. It is not possible for all patients to withdraw steroid treatment. Some require 1mg – 3mg of prednisolone per day to keep well and active and that is fine. However, if possible, the aim should be to withdraw treatment safely.

These are exciting times with a large number of international drug trials planned or ongoing, and hopefully there will be new treatments emerging in the next four to five years.

Finally, what is clinical research doing to help? There is room for improvement across the board in diagnosis and predicting prognosis, and in identifying disease activity and assessing response to treatment. These areas are actively being researched and Justin believes that progress is being made in the understanding of disease onset, the development of novel imaging techniques, blood biomarker discovery and treatment approaches.

The nursing perspective of managing patients with GCA and PMR

Our second speaker was **Madeline Whitlock**, Clinical Nurse Specialist (CNS) in the musculo-skeletal directorate at Mid and South Essex University Hospitals Group.

Madeline explained what it is to be a Clinical Nurse Specialist (CNS); it is a variety of roles but mainly one of educating patients to enable those diagnosed with PMR and GCA to understand their condition and to be able to manage it themselves for most of the time. She also monitors the conditions – looking at blood test results and other drugs patients might be taking for other illnesses (co-morbidities). She talked about the importance for the patient to understand why they're taking what they're taking, and the clinicians' reasoning behind what drugs the patients are being given. Throughout the journey the nurse specialists are there for support, guidance and encouragement.

Madeline talked about the benefits and fears of taking steroids – such as the long-term side effects and the effect on the body. Regular questions from patients are, "am I always going to be dependent on steroids?" or "will my sight be affected if I reduce the steroids?". She says often patients will be on steroids for 18 months to two years, but it can be longer, and the aim is to reduce to the lowest possible dose (5mg or below) to lessen the burden on the body. On the flipside, there's the relief of diagnosis and the benefits of steroids reducing the initial debilitating symptoms and generally allowing patients to return to previous level of independence and retain their eyesight.

Madeline discusses the patient's symptoms at each appointment, remaining vigilant of any flare.

The more the patient understands their condition and medications, the better the compliance is. Patients then need to understand what is inflammatory and what is not inflammatory.

Madeline says it's always important to listen carefully to patients to pick up clues of what the actual problem is. For example, is the headache GCA or is it due to osteoarthritis of the neck? Or to stress? There may be a simple answer to the question but Madeline has to rule out the obvious first. A patient may come to her with shoulder pain, but this may not be a flare of PMR but a flare of osteoarthritis. However, if Madeline is concerned she will discuss with her consultant.

Can Madeline reduce the steroids more quickly if they're really having a detrimental effect on the patient, eg severe mood changes? She will look at the blood test results, discuss the symptoms and perhaps book an ultrasound scan in clinic if appropriate.

Patients often ask about their CRP. Normal CRP in Southend hospital is five and below, but a CRP can be elevated for all sorts of reasons, not necessarily PMR or GCA. It could be an infection, virus or other cause. Blood tests might be required, further investigation or referral back to the GP.

Madeline gives advice on lifestyle, diet, exercise, maintaining a stable weight and ideally on patients recording their blood pressure at home. It's not just about the medications, it's about the whole person. She states that clinicians always have to balance the risk versus benefits of the treatment. It's important for patients to know that long term steroids can make the muscles weaker and incorporating gentle exercise right

of attendees said the quality of the speakers was very good (the rest said good)

from the beginning will have a beneficial impact on maintaining muscle strength and preventing muscle wastage. During the appointment, she stresses the role of PMRGCAuk, and the great benefits and support patients will get from the charity.

Other medications to treat GCA, PMR and Large Vessel Vasculitis (LVV) are Disease Modifying Anti-Rheumatic drugs (DMARDs) and Biologics therapy, as approved by NICE, currently tocilizumab (TCZ) for refractory and relapsing GCA and LVV following strict guidelines and approval. There are challenges as the patient requires TCZ quickly and a very small number of patients may require their first dose intravenously in hospital day-stay, to calm the inflammation of active GCA, visual symptoms and claudication (jaw pain or discomfort while chewing). Normally, the patient will be taught how to administer the TCZ themselves at home, delivered by the homecare company.

Once on TCZ or a DMARD it is important to have a blood test when you are advised in order to monitor the medication and prevent delays in re-prescribing treatment.

One of the challenges of managing patients is staffing numbers across the country. Patient numbers in rheumatology services increase year on year, putting pressures on rheumatology teams to deliver timely and safe care. It's been a challenging time throughout Covid, but teams across the country are working together to maintain a safe service.

Madeline discussed red flags – eg persistently raised inflammatory markers with no obvious cause. She would question whether the patient has night or day sweats, increased fatigue or weight loss and review other routine blood tests for clues. She may then repeat a blood test and seek advice from her consultant who might organise an ultrasound scan and perhaps other investigations as appropriate. A PET scan may be requested to find out the reason for the raised inflammatory markers. There are patients who have grumbling symptoms, and when brought to clinic for an ultrasound scan have been shown to have perhaps large vessel vasculitis if they've got PMR or GCA. The person carrying out the ultrasound must be very experienced in vascular ultrasound. Not all scanned patients have active disease.

Another concern is patients increasing steroids in between outpatient appointments without discussing it with the rheumatology team. Steroids make a lot of symptoms feel better, but sometimes it is not appropriate to increase the steroids unnecessarily, symptoms of osteoarthritis may, for example, require simple painkillers. Instead of altering steroids independently, Madeline has suggested speaking with your rheumatology team first.

The main question asked was why doesn't every hospital have a CNS like Madeline for PMR and GCA? Madeline answered that her role evolved working alongside Professor Dasgupta over the years. He is extremely passionate about PMR and GCA and Madeline has been extremely happy developing her own knowledge of the conditions. She feels that a CNS enhances the patient experience, having more time to discuss patients' concerns, in turn allowing consultants to see patients who are sicker.

Steroid tapering

Our final speaker was **Dr Chetan Mukhtyar**, consultant rheumatologist at Norfolk and Norwich Hospital and PMRGCAuk trustee. Chetan talked about steroid (prednisolone) tapering, the history of steroids and dosing, and his own Norwich Regimen plan.

Cortisone was first synthesised in the 1950s and shortly after, a group of rheumatologists with an interest in GCA gave their patients 300mg of cortisone (which is equal to 60mg of prednisolone) and everyone started to get better. There was no particular rationale to arrive at this dose but it remains a common starting dose even today.

They noted that relapses do not usually occur on doses of 20mg of prednisolone and anecdotally that is true in Chetan's practice. So he is suspicious of diagnosing a relapse in anyone who is above this dose. It's not that it can't happen, just that one has to be really careful of diagnosing that.

In 1975 the first ever clinical trial of corticosteroid was performed and published. Patients were given 60mg of prednisolone for five days and then split into three groups, each following a different regimen: 15mg every eight hours, 45mg every day, or 90mg every alternate day. The outcome was that the people on 90mg on alternate days were most likely to relapse and this is the only definite bit of evidence we have in terms of how we should use steroids for treating GCA.

Chetan's goal was to use steroids in a more sensible way. First, he studied every single prednisolone regimen that had ever been used in any clinical trial. He looked at which regimens had higher or lower incidences of relapsing and from there deduced things not to do.

This included looking at the shape and speed of the taper and the cumulative amount of steroid that is consumed. For example, if you take cumulatively

What was the best part about the day?

"The speakers were excellent"

"Justin Mason's talk was outstanding"

"Feeling part of an understanding and knowledgeable group".

What could we do to improve it?

"More time for questions."

3g of prednisolone, there was a 92% relapse rate; with 4.5g, a 75% relapse rate. So simply by increasing the cumulative amount of steroid would prevent many relapses. From this, Chetan concluded that the amount of the initial dose probably matters; the total dose and how quickly it is delivered probably matters as well. The shape of the taper is also important. Chetan's studies showed that the taper should be slow.

Data from three different parts of the world, showed that steroids could be discontinued in 22 months in Australia and the United States, and 26 months in a French study. There were other reports of between 13 months and six years, but the first three mentioned were so close together and most rheumatologists aim for the two year mark to begin with.

Chetan also considered the logistic pitfalls that he used to encounter in treating GCA where everybody was given the same starting dose regardless of whether they weighed 45kg or 115kg.

The dosing of steroids was also often at the mercy of hospital appointments. Somebody starts at 60mg and is due to see their rheumatologist in four weeks. But if the appointment is then delayed for some reason, then the patient is left on a high dose or is left to make their own decisions. Chetan felt that there should be a fixed plan, as there is for antibiotics, and so he designed what is called the Norwich Regimen which is used at the Norfolk and Norwich University hospitals and a few other trusts. It allows for tailoring based on the patient's height and weight. Each patient is given a plan on diagnosis which shows the starting and end date for steroids. And if there is any variation to the plan, Chetan and his team want to know about it. The patients are also given a helpline number on which they can contact his team.

The reduction plan is over 100 weeks and at the end patients are not discharged, they remain on the books for another 50 weeks.

The typical relapse rate in GCA is between 60% to 80%, ie only 20% to 40% go into remission. Of the first 150 patients treated under the Norwich Regimen since 2013, 69% remain in remission at 150 weeks. Fifteen patients relapsed while they were tapering (at around 5mg) and 20 relapsed after they got down to zero.

In comparison, in the GiACTA trial they gave tocilizumab and steroids for 52 weeks and then observed for another 52 weeks. And at the 104 week mark, only 24% remained in drug–free remission

Chetan hopes to continue collecting these data and to present them in a scientific publication. He explained that if any of his patients has a relapse, they go back to the starting dose of steroid along with the addition of a second drug, and that's almost always methotrexate unless there is a contraindication, in which case it will be tocilizumab or leflunomide unless there's a contraindication, in which case they will have to be on the dose of steroid that keeps the disease under control. Every single relapse is objectively diagnosed, where possible with ultrasound, and this guides their future treatment and planning.

If somebody cannot tolerate a dose of steroids, they will discuss this with that patient who may choose to have a plan with a lower dose of steroids with the knowledge that there is a greater risk of relapse.

As far as PMR is concerned, it is always a diagnosis of exclusion. If 15mg of prednisolone does not work, he will always revisit the diagnosis: that shoulder pain may be osteoarthritis for example. They check cortisol levels for adrenal insufficiency in anyone who has a "relapse" without significant clinical manifestations. A small fraction of people do have genuinely refractory PMR, in which case, they will have to find the lowest dose of steroids that works for them.

The key message from Chetan is that patients should have a clear plan of treatment. There may be deviation from that plan of course, but without having a plan to begin with, how will anyone know that there is any deviation?

Thank you to all of our speakers and to trustee, Dorothy Byrne, who hosted the event. It was very well received by all who attended and we had very positive feedback. (If you missed the event and would like to see a recording of it, please email info@pmrgca.org.uk quoting your membership number.)

Members' corner

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

More members' news on p.15!

YOUR STORY:

DEALING WITH PMR AND PARTNER'S POOR HEALTH

John (82) from London shares his experience with us.

In 2017 I went to my GP with shoulder pain. He diagnosed rotator cuff injury which I put down to having got stuck leaning out of a window and having to twist to release myself some months previous. Neither strong painkillers nor physiotherapy worked. Over a period of around six months, the pain disappeared. Then the other shoulder became painful. Again I sat it out until it more or less disappeared too.

While this was going on I began to be quite anxious about my partner's health and towards the end of 2019, she was diagnosed with having vascular dementia. Soon after, in January 2020, I developed excruciating pain in my hips, groin and buttocks and a severe fatigue. The pain wasn't helped by painkillers.

A newly qualified locum GP picked up on my mentioning that my sister has PMR. Blood tests showed inflammation and he prescribed 15mg of prednisolone. After six hours the pain had completely gone. The relief was so wonderful that the next day I did too much with the consequent suffering and lesson learned.

I've experienced very little pain since but have found fatigue, lethargy and dizziness a challenge. I've tapered fairly smoothly over the 18 months since diagnosis until I got to August this year. By then I was down to 4.5mg but began to experience severe fatigue and sweating so I increased my dose to 5.5mg which is where I now am. I suspect that these symptoms were linked to my adrenals rather than a flare of PMR and will continue to taper slowly over the coming months.

With my experience of PMR, support from the charity's online forum on HealthUnlocked, and through reading lots of scholarly articles I have been able to advocate for myself with my GP and he has been supportive of my slow tapering schedule.

I wonder whether the trigger for my PMR was stress over a period of several years while I was worrying about my partner's health. I'm not sure how much her illness affects my mental health ongoing and obviously there are also worries about the future. For now, I have to think for both of us and brain fog is so tiring. Then there is the exhaustion that comes with PMR and also from the adrenals and it's hard to know what is causing what.

In many ways though, I am fortunate that my experience with PMR is relatively mild compared to many. I joined PMRGCAuk shortly after diagnosis and have felt so supported by both the charity and their online forum. It's good to know that I am not alone.

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

Dear Sarah

I started treatment for PMR at the end of January 2021 (age 69). Prior to diagnosis, I had been very fit and healthy, and particularly enjoyed long distance walking including an annual Ultra Challenge event of 100km which involved a lot of training.

However, with my PMR diagnosis, walking became impossible. With steroids, all pain and stiffness improved wonderfully and I was able to bend, stretch and squat. However, my walking has suffered and I am struggling to build up my distance and pace again. I have approached my walking with caution and have not tried to rush things. I feel fit again but the walking makes me tired and I struggle to exercise two days running. I have just started swimming again and this causes no problems but I feel tired the next day.

I am down to 7mg and on the whole am able to enjoy life, for which I am very grateful. But I would like to try to understand what has happened to me/my joints; what damage has been done; how this is affecting my walking and if any of this is permanent. I am keen to see much further improvement so that I can, hopefully think about taking part in my walking events next year.

I would appreciate your thought on this.

With very many thanks.

Anne

Dear Anne

Thank you for telling your story. Being a competitive athlete living with PMR isn't easy. Even with pain and stiffness well controlled, recovery time post-exercise may be longer. Progression may feel slower. Injuries might take longer to heal. It all can seem hard to make sense of. If the inflammation's under good control, but your body isn't behaving as it used to, does it mean the body has been damaged in some way? What's happening on the inside?

The good news is that, unlike rheumatoid arthritis, PMR doesn't damage your joints. In fact, MRI studies tell us that PMR isn't an arthritis at all. The inflammation of PMR doesn't come primarily from the joint itself, but from the structures around the outside of the joint capsule. This is similar to the way the body naturally tries to repair itself after minor injuries. But in PMR, the inflammation part of this natural repair process becomes rather over-enthusiastic. Too much inflammation causes pain and stiffness. Prednisolone (steroid) settles that inflammation down wonderfully – and for some people it never comes back. But PMR is different for everybody. Sometimes, inflammation does return during or after the steroid dose taper, and the dose may need to be increased again, but needless to say, always take proper medical advice on all matters relating to medication.

People with PMR often experience stiffness and fatigue; many people find that keeping moving is helpful and prolonged sitting isn't good. Warm-ups are crucial! Gentle, whole-body exercise and stretches (especially shoulders and hips) can help PMR symptoms, even when there is a small amount of inflammation. Mixing it up by adding in swimming is a great strategy: give yourself a couple of "rest days" in between more strenuous bouts of walking. We generally advise not to compare yourself to pre-PMR personal best, but to build up your distance or speed slightly week by week.

Even with inflammation well-controlled, there are the effects of the steroids to deal with. While you're taking steroids, your body's metabolism changes. This affects how your body handles and stores energy. Also, your body repair processes are slower when you have steroids on board so you need to be extra careful to build up strength in your tendons and ligaments. Long-term steroids do affect your bones and blood vessels, but exercise is one of the best things you can do to mitigate these effects.

Will I ever be the same again? Yes and no. We are none of us the same person as we were yesterday, or last week. Don't sign up for any expensive events until you're 100% sure you can do them! You might find you ultimately need a small, maintenance dose of medication to keep that inflammation settled down (not because you're doing anything wrong; PMR can just be like that). Either way, please, never think of yourself as "damaged" in any way: whether on or off medication, our bodies carry the history of everything they've seen and done. I don't call that damage; I call it life experience. You may need to slow down a little: but never stop moving forward.

(With thanks to Anne O'Brien for sense-checking.)

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.

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Pmr Gca SCOTLAND

Notes from the Chair – Richard Cuthbert

I am delighted to devote these notes to a report by trustee, Lorna Neil, on her involvement in recent training of medical professionals. This is an area where our charity has provided funding in the past and we would be interested in doing so again.

Southend Ultrasound Workshop – Lorna Neil

In September I was finally able to visit Southend where Professor Dasgupta and his team were running the 8th International Ultrasound Workshop and Symposium in GCA, PMR and LVV. This was originally due to occur in March 2020 which was of course cancelled, as were subsequent hoped-for dates, but eventually a shortened version, without international speakers or delegates, could take place.

My impressions were of many dedicated clinicians giving up their time to learn skills which would benefit their patients and revelling in the opportunity to engage face to face again with other like-minded individuals. As always, the personal contacts made, both formally and informally, with doctors, nurses and others who are enthusiastic about their roles in treating patients with GCA, LVV and PMR were so helpful to a patient-based charity such as PMR-GCA Scotland and it was delightful to find a small group of enthusiastic Scottish rheumatologists training up to expand ultrasound services for those of us in Scotland.

Concern for patients was evident throughout. I was especially struck by Professor Dasgupta's warning at the start that "a low probability patient does not mean that they are not a sick patient" and that "a high probability of GCA can mean a high probability of another serious illness". Patients can feel abandoned when a negative diagnosis from one hospital department leaves them with continuing symptoms but unaware of how to restart the process of looking for an alternative diagnosis in the current atmosphere of "not bothering the NHS". Suggestions from rheumatology for the next step at this stage both reassure the patient and aid the GP.

The turnout of volunteer patients was indicative of the respect and appreciation they had for the staff and their treatment at Southend. Conversations with many of them confirmed this fact. At one point I myself was roped in to provide yet another patient for doctors to learn on and can confirm that the procedure is not only painless but comfortable enough for me nearly to doze off when provided with a hospital bed to lie on in a warm room. The only downside was getting up with an earful of the gel which is applied to the ultrasound probe and which then ran out into my hair. It must have been interesting for the trainees when trying to find and examine my temporal arteries, since I had had biopsies on both sides many years ago! Thinking back to that time reminded me why patients are so in favour of ultrasound rather than biopsy as a first diagnostic procedure wherever possible. Gel which was washed out in a minute was certainly preferable to stitches, a lump and a bald patch, all of which lasted more than a week.

PMR-GCA Scotland has in previous years supported Scottish rheumatologists with small grants to enable attendance at Southend Ultrasound Workshops and Symposia but this was the first time any of the trustees had had the chance to appreciate the high quality of the teaching, technology provision, venue and organisation. I only hope that the courses continue to run, here and elsewhere, and that more and more of the rheumatological community are able to acquire the skills of vascular ultrasonography to quickly confirm a diagnosis of GCA/LVV – or just as importantly to rule it out and thereby allowing the patient to avoid unnecessary high doses of steroids.

Members' corner
Continued...

Can you help us?

PMR-GCA Scotland operates with a small committee of trustees and volunteer members. We are always looking for more people (members, partners, friends or supporters) who can help us to run and expand the activities of the charity. In particular we need help in the following areas:

Treasurer – maintaining the books and records for the charity and producing regular accounting information. Our annual income is about £6,000 and formats and templates are available to assist with the processes.

Membership secretary – maintaining membership records, distributing information packs to new members, issuing paperwork for AGM and Zoom meetings and distributing Newswire.

If you would like to help in these or any other areas, or can offer suggestions for potential recruits, or simply to find out more about what is involved, please contact Richard Cuthbert at chair@pmrgcascotland.com

Photo competition winners

Thank you to all the members who sent in their lovely images in the summer. We had around 200 to choose from for our calendar and it was extremely difficult to narrow it down to the 13 images we needed. Well done to Ann Williamson, John Minter, Julia Marsden, Rosemary Marsden, Bill Jopson, Fiona McKenzie, Mattie Lowther, Maria Pickles, Barbara Abrahams, Viktoria Heard, Erica Bates, Heather Green and Carole Ladd whose pictures can be found on the cover and pages of our calendar. (The calendars were extremely popular and sold out quickly.) Notelets will be available in the new year – we will have more details in the spring.

Running for charity

Thank you to **Fiona Turnbull** who ran the Cambridge half marathon in October raising funds for us. Fiona was diagnosed with PMR in October 2020 and is fortunate to have been able to carry on enjoying her running. Her aim was to raise £750 and as we went to print she had already raised nearly £900.

Photo: Fiona with her husband Paul

SUPPORT GROUP CONTACTS

Our network of groups around the country is growing!

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