



New PMR guidelines are a first



The implications for this are pretty tremendous, because it means that international collaboration on research will now be easier, and doctors and patients will benefit from sharing best practice. A few national PMR guidelines such as recommendations of the British Society of Rheumatology, the guidelines of the German Society of Internal Medicine, or the guidelines of the Dutch College of General Practitioners had been published previously. However, there is a need for international guidelines to reduce the variation of practice not only across primary/secondary care but also across different health care systems.

Much credit is due to the vision and dedication of the leaders of the group, Professor Dasgupta from the UK, Professor Matteson from the US, and Professor Dejaco from Germany, [Continued on page 2>](#)

At the start of 2015 we received the great news that the new international guidelines for PMR have been finalised and approved by EULAR, the European League Against Rheumatism and ACR, the American College of Rheumatology. This transatlantic venture is the first time ever that a set of guidelines for a rheumatological condition has been created and agreed on both sides of the Atlantic.

INSIDE THIS ISSUE

- 2 HEALTH & WELLBEING**
What are Steroid Cards?
- 3 RESEARCH UPDATE**
Sara Muller, Research Fellow, Keele University gives us the latest research news
- 4 PMR GCA SCOTLAND**
Take some time for yourself
- 5 SUPPORTERS**
Pam Daw, Rob Murton and Jane Dobson
- 6 UPDATES**
Support Groups Events and a Research Opportunity
- 6 SUPPORT GROUP CONTACTS AND UPDATES**
All the contacts you need!
- 7 ANNUAL GENERAL MEETING AND MEMBERS DAY**
An invitation and RSVP form
- 8 ANNUAL GENERAL MEETING AND MEMBERS DAY**
Programme and how to get there

 **NATIONAL HELP LINE**
0300 111 5090

PMRGCAUK is a registered charity established to meet the needs of people with these debilitating conditions by raising awareness, promoting research and offering support.

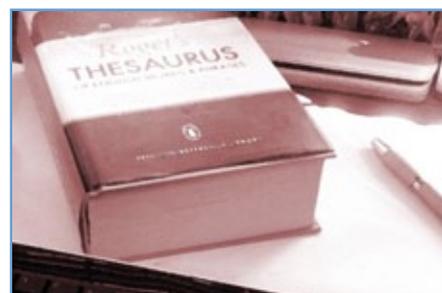
SAVE THE DATE:



AGM and Members' Day - London

Wednesday 17th June 2015

We'd like to invite all members to our AGM and Members' Day. We're delighted to welcome two speakers covering subjects of interest to anyone with PMR and GCA. For more information, go to the back pages where you'll find the programme and official information. Please send us the RSVP on the invitation form if you'd like to attend. We're looking forward to seeing you!



FEATURED SUPPORTER

JANE DOBSON & NineVoices

What's the link between PMRGCAUK and Bromley & North Kent support group member Jane Dobson's love of poetry, a local writing group, short stories and supporting PMRGCAUK? Find out more inside.

who forged a wonderful spirit of collaboration that included everyone as equals, including the seven patient representatives. These included Lorna Neill and Jean Miller from PMR-GCA Scotland, Pamela Hildreth from PMR-GCA UK North East Support, Kate Gilbert and Hannah Padbury from PMRGCAuk.

The guidelines are the result of a two-year process of meetings, research activity and discussions, using a process called GRADE, which is a standardised format for evaluating the quality of research evidence. A 'core' panel reviewed all the published research papers on PMR and scored them for the quality of the evidence.

'One of the things that really struck me was that a great deal of the so-called 'scientific evidence' that people quote in relation to PMR is really of a very low standard, in the sense that it is based on a single study of a very few people,' said Kate Gilbert. 'Time after time the working group had to judge a published article as giving 'poor' level of evidence for its findings. It made me even more sure that a great deal more research is needed. For example,

the group couldn't make an evidence-based recommendation on whether short-term or long-term steroid therapy is better in terms of patient outcomes, because the evidence simply isn't there.'

The research evidence was used in discussion by a 'voting panel' to generate answers to a set of 22 questions. Questions were formulated on issues that are close to patients' hearts, such as the 'best' starting dose for prednisolone, whether NSAIDs (such as ibuprofen) are acceptable to use in PMR cases, and what are the pros and cons of a faster against a very slow reduction in steroids. Incidentally, the panel came out very strongly against the use of NSAIDs instead of corticosteroids.

Clinicians were very concerned about treatment options that might raise the risk of 'relapse'. There was talk about patients whose condition is under control as being in 'remission'. Patient representatives had some reservations about the term 'remission'. Surely, they argued, the illness is still there, just grumbling along in the background. Our clinical colleagues

in the working group really did listen to our concerns and said that they learned a good deal from us.

EULAR and ACR have now endorsed the recommendations. In future newsletters we will present more detail and the factors that the panel were taking into account. In the meantime it's important to be clear that the guidelines are meant for general use – to inform diagnosis and decision-making, but they don't provide a 'prescription' for how every individual case should be treated. There is a lot of individual variation and doctors and patients together will always have to take individual factors into account. However, the guidelines give us a strong starting point for developing best practice in referral and treatment. As Professor Dasgupta said: "It's great news and a step forward for PMR". Now to take on the challenge of implementation!

The guidelines will be published in full by the BSR. For a summary, please go to the link in the Latest News section of our website: www.pmrzcauk.com

HEALTH & WELLBEING: What are Steroid Cards?

BLUE STEROID CARDS

Blue steroid treatment cards are issued by your prescriber, doctor or pharmacist. People on long term steroid treatment should carry the card and/or wear a medical emergency identification bracelet or equivalent. This gives details of your dose, your condition, etc, in case of emergencies. For example, if you were knocked unconscious in an accident, or in urgent need of an operation, it is important that doctors know that you take steroids and need to take them regularly. If you are currently taking steroids, or have taken them in the last year, it is also important that you tell everyone involved in prescribing you medicines and giving you medical treatment, including your doctor, dentist, nurse and pharmacist. More information can be found at www.patient.co.uk/health/oral-steroids

Thanks to Clare Marshall (Peterborough Support Group Organiser/Helpline Volunteer) for this information

YELLOW STEROID CARDS

The Yellow Card Scheme is used to make pharmacists, doctors and nurses aware of any new side-effects that your medicines may have caused. For more information or if you wish to report a side effect you can do this online at : www.mhra.gov.uk/yellowcard. It is helpful if you have your medication and/or the leaflet that came with it when you complete the report online so that you can refer to it for basic information.



RESEARCH UPDATE MARCH 2015

Sara Muller, Research Fellow, Keele University gives us the latest research news

There have been a number of papers published in recent months that have shown increased risks of vascular problems in those with GCA and/or PMR. In a UK study, people with GCA were approximately twice as likely to develop an aortic aneurysm as people without GCA. However, the risk was still relatively small, with 2.8 aneurysms seen for every 1000 GCA patients per year. Whilst an American study showed a similarly increased risk of deep vein thrombosis and pulmonary embolisms (blood clots in the lungs).

A further UK study, in which I was involved, showed that people with PMR were approximately 2.6 times as likely to have a vascular event (e.g. heart attack, stroke) as those without PMR, after allowing for other things that cause vascular problems. Again, this should be interpreted in context, and is equivalent to around 36 such events for every 1000 people with PMR per year. These studies used data from GP records. Whilst these data are of a good quality and have been used for several PMR and GCA research projects, they do have their limitations. In particular, it is important

to remember that people with PMR/GCA are likely to have had more investigations than people without a chronic condition, and it is therefore reasonable that more people with the PMR/GCA might be found by chance to have an aneurysm, or other condition that has few or no symptoms.

Researchers from Thailand and the USA have conducted a review of all the literature on PMR/GCA and cancer. They showed a small increased risk of cancer, but they were keen to stress that the studies they included in their review may be biased in several ways, and so no firm conclusions can be drawn about whether PMR/GCA causes cancer.

There is good news from a recent GCA study in the USA that showed that visual symptoms in GCA have declined over the last 50 years and that recovery from such symptoms is improving. They highlighted that jaw pain on chewing is associated with a higher likelihood of sight problems.

Of particular interest to PMRGCAuk members might be Dr. Helen Twohig's recent interview study

about patients' experiences of PMR. Her paper is entitled "I suddenly felt I'd aged": A qualitative study of patient experiences of polymyalgia rheumatica (PMR)', and gives a lovely summary of her interview study around 5 themes: pain, stiffness and weakness; disability; treatment and disease course; experience of care; and the psychological impact of PMR.

In terms of studies of treatments, a small, non-randomised study from Spain has considered patients with GCA who did and did not receive angiotensin II receptor blockers (drugs usually used for high blood pressure and other vascular conditions) alongside steroids for GCA. Those taking these drugs had longer disease-free survival, reduced relapse rate, and shorter time on higher (>10mg) steroid doses. They also tended to have fewer steroids in total over the first year of treatment. However, this study was not very large, and as people were not randomised to receive treatments or not, it may be that there is something about who was taking these other drugs that was important in determining their GCA outcomes.

There are still lots of on-going studies in PMR and GCA across the country including Professor Dasgupta's study into using Leflunomide alongside steroids in early PMR, the UK GCA Consortium and ADDRESS-PMR studies in Leeds, led by Dr Sarah Mackie and the PMR Cohort Study here at Keele from which we hope to have some early results in the next 12 months.

Dear Readers

I thought that, for this edition, I would take us away from the two conditions which probably haunt many. We have written several articles telling you about what is going on in Scotland with the charity and how we are working with other agencies in an effort to improve diagnosis and care. Part of self-management is taking some control of your care and life along with your health professionals. This is a very important part but we also need to take time for ourselves too. There are a number of techniques that you can use from music to art to sleep – all hopefully intended to aid relaxation, which can be a great healer. Visualising something beautiful, desirable or meaningful to you can help provide a focus for this relaxation

The image of Scotland may conjure up anything from the glorious wilds of the Highlands and Islands; the skirl of the pipes (love them or not); kilts; haggis; whisky (did you know it was invented in China?); porridge; Edinburgh rock; another British accent which may include unusual words; football or even battered Mars Bars (believed to be created for English visitors) but does it ever make you think of fine jewellery or chocolate? Possibly not.

Although cocoa isn't grown in Scotland, we really don't have the climate, it doesn't prevent chocolatiers from selecting the very best ingredients to produce the finest chocolate with a distinctly Scottish twist. These artists may incorporate Scottish cream, butter, foraged berries, herbs, whisky and other liquors (including Scottish-made gin) into the final product. There is even a chocolate trail which would take you through some 78 sites from the south-west to the north-east including Sanday (one of The Orkneys) and Shetland.



Imagine drinking a freshly made hot chocolate at a café in Durness (right on the mainland north coast) looking over long sandy beaches with turquoise waters glinting in the summer sunlight or perhaps in the depths of winter while snuggled in front of a roaring log fire.

You may think me cruel to have you imagining something which may be on your "forbidden" list but I don't think an occasional indulgence should cause difficulties – as long as it is very occasional, a treat. Very rarely someone may have a chocolate allergy, although it is more probably a constituent but trace ingredient in the finished product, so hopefully you have your own little occasional indulgence (mine is tablet, which I dare not keep in the house). I actually keep a small amount of good quality chocolate because I find it cures or certainly eases my headaches (I think that's because my headaches are usually stress related and chocolate soothes some of my troubles).

And jewellery? Scotland isn't a place to find diamond mines (yet) however we do have gold in some burns and sapphires from the islands but the stones Scotland may be better known for are semi-precious agates and quartz. When polished up and set into Stirling silver kilt pins, rings and brooches or Sgian Dubhs, to name a few; each piece as unique as

the landscape they are from. I have a brooch which has two Cairngorm quartz stones set in it (a beautiful amber colour) and just looking at it can transport me back to the mountains.

I hope that these little snapshots have allowed you a temporary escape and introduced you to the idea of using images, memories or your imagination to help you get through a difficult spot. For Scots readers, a trip down memory lane; for those lucky enough to have the scenes you have conjured up on your doorstep, perhaps a feeling of fortune. For any reader who hasn't yet crossed this British border, take your time and perhaps when you feel ready, consider the journey for real.

Bea

Bea Nicholson
Chair of PMR-GCA Scotland



HELPLINE

0300 777 5090

www.pmrangca.org.uk

Registered Scottish Charity No
SC037780

Registered address
Forest Lodge, Foulden,
Berwickshire TD15 1UH



Pam Daw, local historian and PMRGCAuk member, lives at Castlemeads Court in Gloucester where most apartments are privately owned and people are of retirement ages. Pam held a small free event for her neighbours to tell them more about PMR and GCA and encourage support for the charity, raising £100 in donations. She told us

'My neighbours were fantastic, generous, and a captive audience! I am grateful to them.'

We'd like to add our gratitude – everything raised will go towards the support we provide.

Featured Volunteer: Rob Murton

Volunteers are essential to the charity's survival. And a key volunteer at PMRGCAuk is Rob Murton, who sends out our information packs (and this newsletter!) as well as monitoring our info@pmrgcauk.com mail.

Rob's experience of PMR began after he fell over.

'I thought I'd just hurt my hip, but it spread to my shoulder. Then I couldn't get out of my van – I was working as a courier at the time. The next thing I knew, I couldn't get out of bed. My hands swelled up.'

He was lucky.

'I had the right GP at the right time, who saw PMR straight away, got me tested and started me on a high steroid dose.'

It took Rob around two and a half years to get off steroids, and he considers himself over PMR.

'Don't get me wrong – I still get aches and pains, but touch wood, no flare ups.'

In 2013, when Rob was looking for information on PMR, he came across the charity's website, and saw they were looking for someone to help. Since then he has become central to the support provided to people looking for information.

'It gives me an interest, and keeps my mind occupied' says Rob. 'Volunteering stops you just sitting there. Sometimes people can feel trapped if they can't go out. They don't realise that they can help – but by using the internet, it doesn't matter if you're at home. You can still help – and it keeps you interested, and keeps your mind off any illness.'

If you are interested in volunteering for the charity, we are currently recruiting new Helpline volunteers. For more information, please call 0300 999 5090 or e-mail sophy@pmrgcauk.com

FEATURED SUPPORTER

Jane Dobson and NineVoices

Jane, a member of NineVoices, is a Kent-based writing group.

'My illness began very suddenly two and half years ago after an eight mile walk. The pain started in my hands. Within three days I felt like death, unable to bear a sheet at night and using a wheel chair by day. Blood tests showed my CRP was 168 (normal is less than 4) and I was referred to a Rheumatologist. I didn't have classic PMR symptoms. Twelve months later, despite quite a high steroid dose, I was experiencing joint pain too. On a clinic visit, a locum consultant ordered a PET scan which revealed I had both GCA and rheumatoid arthritis. I am very lucky that GCA was picked up. Twelve

months later, I have experienced a lot of GCA flares but in between manage life quite well. I don't want to be defined by illness. I am so lucky to have a wonderful family and friends. The sunshine helps! I was practically pain-free during a recent two week holiday in Tenerife.'

Writing helped Jane escape. It had always been close to her heart.

'At a very young age – about 6 - I began scribbling under the bedclothes using a torch,' Jane said. 'I've written short stories and a novel and am working on another, although I'm finding this difficult due to my health. So I returned to my first writing love: poetry. Most of my poems come from an experience or incident. Sometimes

the whole thing appears. Once I had to stop the car and write it down. Usually, though, it takes me months or years to write and re-write. I find it cathartic. It's a release from the humdrum of life (and sometimes pain).'

For Jane's 70th birthday, members of the group surprised her by producing an anthology of her poems, given to guests at her birthday lunch. Now the group is selling the anthology at £5.00 per copy, and holding a short story competition, with funds raised also going to the PMRGCAuk charity.

To buy Jane's book, contact info@pmrgcauk.com

To find out about the competition, visit www.ninevoices.wordpress.com.

SUPPORT GROUPS - EVENTS



North West: 'What Every Clinician Needs to Know'

As this newsletter went to press, the North West Support Group (www.pmrgcauk-nw.com) was holding a regional event: 'What Every Clinician Needs To Know' at the Royal Oldham Hospital, Oldham. The event was chaired by Dr Vinodh Devakumar, Regional Chair of the British Society of Rheumatologists and included expert speakers Dr. Sarah Mackie and Professor Bhaskar Dasgupta, and interactive focus group discussions.

Poly Puts the Kettle On in the South West

On April 16th at 2pm both the Taunton and Plymouth groups are holding a 'Poly Puts the Kettle On' tea party – an event that combines raising awareness of PMR and GCA with an afternoon of entertainment and fun. As well as the tea and cakes, Taunton's event includes a live samba band and book signing by crime writer Hilary Bonner.

The Plymouth Event will be held at Weston Mill Sheltered Housing Centre, Weston, Plymouth, PL5 1E5. To find out more, call: **07712 277622**

The Taunton Event will be held at The Memorial Hall, Paul Street, Taunton, TA1 3PF. To find out more, call: **01823 663911** or e-mail pmrgca.southwest@yahoo.co.uk

RESEARCH OPPORTUNITY

Open Consultation - Doctors and Patients with Experience of Giant Cell Arteritis

The British Society for Rheumatology and Royal College of Ophthalmologists, Giant Cell Arteritis Guidelines Group are developing clinical practice guidelines for giant cell arteritis (GCA), to help doctors recommend the best treatments for their patients.

To take part, complete their survey at: <http://goo.gl/forms/1PQyMbv8cH>. This survey is completely anonymous and you will not be identifiable from your answers unless you want to be. If you are willing to take part in future consultations along similar lines you can provide your email address in the form or alternatively send a separate email to: gcasurvey2015@gmail.com

Support group contacts

The very latest information for all support groups can be found at www.pmrgcauk.com including details of speakers and local events. If there isn't a group near to you why not consider starting one – a problem shared is a problem halved! We will help you to get started.

CAMBRIDGE

Organiser: Dale Hodgson
Phone: 0300 999 5090
Email: cambridge@pmrgcauk.com

EAST ANGLIA

Organiser: Maryan Fidler.
Phone: 0300 999 5090
Email: eastanglia-pmrgca@outlook.com

GREATER LONDON

New group just started!
Phone: Sophy on 0300 999 5090 for more information

LINCOLN

Organiser: Rob Murton
Phone: 0300 999 5090

NORTH EAST ASSOCIATE CHARITY

Organisers: Pam Hildreth & Mavis Smith
Phone: 01287 623 334
E-mail: pmrgcafightersne@googlemail.com
Website: www.pmr-gca-northeast.org.uk

BROMLEY & NORTH KENT

Organiser: Penny Denby
Phone: 0300 999 5090
Email: northkent@pmrgcauk.com

MANCHESTER & NORTHWEST

Organiser: Ann Chambers
Phone: 01942 895 806
Email: northwest@pmrgcauk.com
Website: www.pmrgcauk-nw.com

PETERBOROUGH

Organisers: Clare Marshall/Lorna Edmonds
Phone: 0300 999 5090
E-mail: peterboro@pmrgcauk.com

PLYMOUTH

Organiser: Sally Ann Morgan
Phone: 0300 999 5090
E-mail: pmrgca.plymouth@yahoo.co.uk

SCOTLAND ASSOCIATE CHARITY

Bea Nicholson (Chair)
Phone: 0300 777 5090
E-mail: info.scotland@pmrandgca.org.uk
Website: www.pmrandgca.org.uk

SOUTHEND/ESSEX

Organiser: Hannah Padbury
Phone: 01702 587 436
E-mail: southend@pmrgcauk.com

TAUNTON

Organiser: Wendy Morrison
Phone: 0300 999 5090
E-mail: pmrgca.southwest@yahoo.co.uk

SURREY

Organiser: Shirley O'Connell
Phone: 0300 999 5090
Email: surrey@pmrgcauk.com

SUSSEX/SOUTH COAST

Organisers:
Christine Young & Catherine Pickersgill
Phone: 0300 999 5090
Email: pmrgcasouthcoast@btinternet.com

Annual General Meeting and Members' Day

DATE: Wednesday 17th June 2015

TIME: 11.00 am - 4.00 pm

VENUE: National Council for Voluntary Organisations (NCVO),
in Regent's Wharf, Room 11a/12a, 8 All Saints Street, London, N1 9RL

We cordially invite all members to attend PMRGCAuk's AGM, which will be followed by our annual Members' Day, a participative event for members and friends of PMRGCAuk.

Attendance at the AGM will be free of charge; however for the Members' Day we will be requesting a contribution of £10 towards costs, to include a buffet lunch and refreshments. During the day, we'll be hearing from specialist speakers, taking part in workshop sessions and above all, getting to know other people who are living with PMR and/or GCA.

Please fill in and return the slip below to register if you would like to come. Alternatively, you can email info@pmrgcauk.com. Payment for the lunch can be sent by cheque/postal order (made out to PMRGCAuk) with the slip, or by cash or cheque at the event. We look forward to seeing you on the day!

Best wishes,

Dr. Kate Gilbert
Chair of PMRGCAuk

PMRGCAUK

I would like to attend the AGM and Members' Day on 17 June 2015

Name

Member of PMRGCAuk? Yes No

Address

Email*

Telephone

Do you have any special access requirements? (e.g. visual impairment, wheelchair user)

Yes No

If yes please state:

Do you have any special dietary requirements?

Yes No

If yes please state:

I enclose a cheque for £10 / I will make a donation on the day (please delete as appropriate)

Please let us know if you are coming: e-mail info@pmrgcauk.com or post this slip to BM PMRGCAuk London, WC1N 3XX

* We'll email the Charity's draft accounts/annual report to members providing an e-mail address 7 days before the event.



AGM/Members' Day 2015

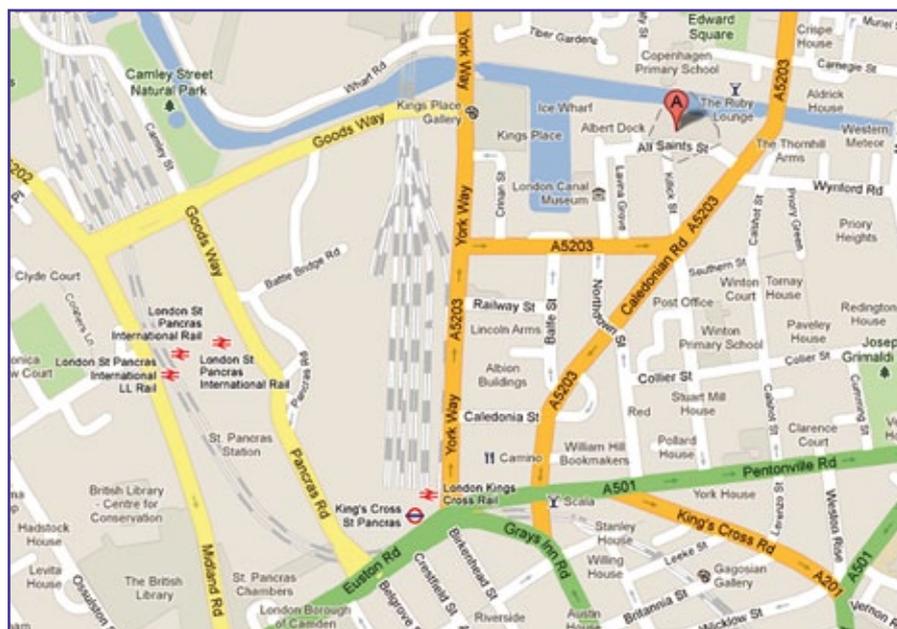
Wednesday 17th June 2015

Programme

11.00 am	Arrival and registration
11.30 am	AGM
12.00 noon	First Speaker: Professor Eoin O'Sullivan: GCA and General Eye Care (with a focus on the effects of steroid use)
1.00 pm	Lunch
1.30 pm	Second Speaker: Dr. Toby Helliwell: PMR – a GP's Perspective
2.30 pm	Refreshment break
2.45 pm	Group discussions/networking
3.45 – 4.00 pm	Closing discussions

Directions

The NCVO is about 10 minutes' walk from Kings Cross mainline station. The building has disabled access. Details on the venue including parking, access and directions can be found on <http://www.ncvo.org.uk>



TRANSPORT

Buses: The 17, 91 and 259 buses pass by NCVO. The 390 bus route passes down York Way, a short walk from NCVO.

Trains: Trains to King's Cross, St Pancras or Euston.

Tube: Piccadilly, Circle, Victoria, Hammersmith and City, Northern and Metropolitan lines all pass through King's Cross Station.

More travel information can be found on www.tfl.gov.uk