

You are not alone

Polymyalgia Rheumatica and Giant Cell Arteritis

Newsletter Autumn/Winter 2012

Who does what?

A frequent question from our Members is:

"just how did we come about and what do we really do?"

People at our group meetings often ask us who they should contact for this and that or how just six of us manage to run this North East Charity with a large number of members, especially on the forum. We thought we would answer that question.



Mavis Smith (GCA) *Trustee Chair*: Responsible for publications. Liaises with Support Groups, the National and Scottish Charities and relevant organisations.



Pam Hildreth (PMR) *Trustee Secretary*: Runs Area 1 Middlesbrough group. Manages the website. Moderates the Forum. Applies for funding specific to Teesside. Gives talks to Medical students at the James Cook University Hospital.



Christine Beet (PMR) *Trustee Forum Administrator*: Responsible for operation of the internet forum. Co-ordinates Moderators (see separate article on page 6).



Lynne Boyle (PMR) *Trustee Membership Co-ordinator*: You speak to Lynne over the phone when you join or renew. Arranges Guest speakers for Gateshead. Attends Area 1 & 2 meetings. Lynne is a Trustee of PMRGCAuk.



Margaret Wright (PMR) *Trustee Vice Chair and Project Co-ordinator*: Responsible for running Area 2 Gateshead meetings. Oversees various projects, ie making the DVD, charity badges. Fundraises for Gateshead area and the Charity as a whole.



Alan Tailford (Healthy) *Trustee Treasurer*: our little treasure, just what would we do without him. Alan keeps all our accounts in order, tells us what we can spend, when we can spend and how to manage our members' funds to get the best value for money.

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Merry Christmas



Our Christmas Drummer by *Mariarita Moss, 89, an email member who resides in Norwich.*

Need help?

Want to join?

Please get in touch:

PMR&GCA UK North East

Tel: 0191 411 1138

Email: pmr-gcafightersne@googlemail.com

www.pmr-gca-northeast.org.uk

www.pmr-and-gca-forum-up.co.uk

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All except Christine, who lives in France, take telephone calls from both new and existing members, monitor and answer emails daily. We work closely as a team in constant contact to keep this North East charity running. Boy does our wine look good at the end of a busy day!

Oh and one thing I forgot, we are all volunteers and Silver Surfers.



Inaugural Meeting in London on 14 March 2008.

In March 2008, Pam Hildreth and Mavis Smith travelled to London to meet Professor Dasgupta, a Consultant Rheumatologist and leading expert on PMR and GCA. 25 people attended the meeting paying their own expenses. The outcome was a new Charity was launched called PMRGCAuk.

Following that meeting, Pam and Mavis returned home determined to set up support groups to cover the North East of England. In April that year, they were joined by Margaret Wright and later Lynne Boyle. Alan Tailford was 'kidnapped' as soon as he retired as a Police Inspector from Northumbria Police and persuaded to become our Treasurer. From those early days over four and a half years ago, we have gone from strength to strength, with over 150 members and over 500 members on our Forum. The website has on average 30,000 viewings per month. In October 2010, we became a registered charity with six Trustees and three Patrons, PMR&GCA UK North East Support exists.

UPDATE

ON RESEARCH & CLINICAL TRIALS IN PMR & GCA

(A glossary of the acronyms used below is at the end.)

1. An international EULAR & ACR group has developed classification criteria for PMR

PMR-type symptoms can be frequently due to other conditions and the criteria lay down simple rules – a scoring algorithm – for assessing suspected PMR. **The criteria recommend that all patients should be assessed with ultrasound of shoulder and hips.** We hope it will make the diagnosis safe and prevent misdiagnosis. As part of the project, the group is also trying to use this research to develop PMR-specific blood tests.

The paper is considered so important that it will be jointly published by the two leading journals in Rheumatology. The classification criteria will also make sure the right patients are included in clinical trials for PMR. This will address the unmet need for finding better treatment for PMR with lesser long-term side effects.

2. Clinical and patient reported outcomes in PMR. Assessment of PMR is very important since it determines the treatment and doses of steroids that are used. Use of steroids is often quite arbitrary since pain can arise from other wear and tear conditions.

An international EULAR and ACR group has tried to address this unmet need and has developed standardised assessments for PMR. It finds that six areas of symptoms and signs are important for assessment of disease activity, regulating steroid dose and considering other therapies in PMR. These are:

- Global pain (rated between 1 and 10)
- Morning stiffness (in minutes)
- Hip pain (rated between 1 and 10)
- PMR-related physical difficulties (such as ability to rise, reach, dress, walk, perform day-to-day activities – rated individually 1-3)
- PMR-related depression, emotion and impact on social roles
- Inflammatory markers such as CRP or ESR

These assessments above should be used in clinics and in future clinical trials and **steroid dose adjustment should not be done solely on the basis of blood tests.**

This paper has been accepted for publication and will be published in the journal of Rheumatology.

3. Annexin as a laboratory test of disease activity in PMR and GCA.

Better specific laboratory tests for PMR and GCA are urgently needed. Research is ongoing to see whether annexin – a substance released by inflammation which regulates steroid action – can be used to see how well a patient with either PMR or GCA is doing. With the help of a grant from the British Heart Foundation, this work is almost completed.

4. ACR & EULAR recommendations on PMR To make the guidance on PMR uniform and worldwide, the EULAR and ACR have commissioned joint recommendations on PMR. A systematic review of published and presented papers on all aspects of PMR will be undertaken and will be discussed at four face-to-face meetings over the next year. The panel will include experts as well as patients (including PMRGCAuk representatives) to agree opinion on the diagnosis, investigations and management of PMR.

5. Ongoing clinical trial of Interleukin 17 and Interleukin 1 blockade in PMR. Better treatment of PMR is urgently needed with reduction in side effects of long-term steroids. This trial looks to see whether single drip infusions of two medicines – **antibodies to IL 17 and IL 1** – can control PMR symptoms and signs without steroids. They may be used to block inflammatory molecules that are increased and may cause PMR. The trial may offer future alternatives for people who suffer PMR flares and/or steroid side effects.

6. Clinical trials of delayed release Prednisone (with Lodotra) in GCA and PMR. Steroids timed for release at the time of the maximum elevation of inflammatory substances in the blood early in the morning may be more effective in the treatment of symptoms of GCA as well as PMR – such as early morning pain and stiffness, which are important causes of disabilities in both conditions. Improvement in these symptoms will influence quality of life, and may enable earlier withdrawal of steroids and reduce side effects. The GCA trial is shortly due to start in Essex. The PMR trial is worldwide and will start mid-2012.

7. The use of Tocilizumab to block the effect of Interleukin 6 in PMR and GCA. Interleukin 6 is an inflammatory substance that is responsible for elevation of ESR and CRP and causes a lot of inflammatory signs and symptoms in PMR and GCA. This trial, using single drip infusions of Tocilizumab that neutralises Interleukin-6 in PMR, is starting at the Hospital of Special Surgery in USA. A similar trial in GCA in UK is in the design phase. *This is an exciting future therapy since case reports have shown it to be very effective and may be a 'game changer' in PMR and GCA. However, Tocilizumab is expensive and the other drug being studied in PMR and GCA is the readily available Leflunomide.*

8. The TABUL GCA Study aims to compare the diagnostic accuracy of temporal artery ultrasound to temporal artery biopsy in new cases of suspected Giant Cell Arteritis. Early diagnosis of GCA within hours and days is vital and better ways of confirming diagnosis without biopsy are needed. This Health Technology

Assessment-funded ongoing trial has currently recruited 100 patients in two centres (Southend and Oxford) and hopes to totally recruit 400 patients to make recommendations about the use of temporal artery ultrasound in GCA. Ultrasound is performed on the inflamed blood vessels over the temples and axilla to see the signs of the 'Halo sign' – produced by inflammatory swelling affecting the vessel walls.

9. An international study (DCVAS) is underway to classify various types of Vasculitis and this includes Giant Cell Arteritis. It is important to be able to recognise the different types of blood vessel inflammation since the treatment varies according to diagnosis. This international study is looking at all forms of vasculitis including GCA to develop diagnostic criteria for GCA and enable earlier recognition of the condition.

10. Fast-track pathway for GCA *To improve the early diagnosis and treatment of GCA; to prevent loss of sight.* Early diagnosis of GCA within hours and days is vital and patients need to be treated quickly, and urgently referred to specialists such as rheumatologists and eye specialists. Such a fast-track pathway has been implemented in South Essex that will enable patients with suspected GCA to come to specialist management within hours of developing symptoms.

The ACT FAST campaign for strokes has been very successful nationally in reducing death and disability due to strokes by infusing 'clot buster drugs' within four hours of developing symptoms. 'Time is sight' in GCA, and patients with jaw and tongue pain and visual symptoms such as blurred and double vision need similar urgent treatment with intravenous steroids. Outcomes from this service are being evaluated and may become the national model for GCA services across the country.

However, it is the task of patient charities such as PMRGCAuk and regional groups to raise public awareness so that patients with such symptoms contact their doctor urgently.

Key:

- EULAR:** European League Against Rheumatism
- ACR:** American College of Rheumatology
- CRP:** C-reactive Protein (blood test)
- ESR:** Erythrocyte Sedimentation Rate (blood test)
- TABUL:** Temple Artery Biopsy & Ultra-Sound
- DCVAS:** Diagnostic Criteria for Systemic Vascular Arthritis
- CPK:** Creatine PhosphoKinase (blood test)

The foregoing has been reproduced with the kind permission of Mrs J Knott East Anglia Support, the information was supplied by Professor Dasgupta.

Middlesbrough Area 1 News

September

Pam Hildreth, Secretary and Trustee, opened the meeting by welcoming all members and potential new members.

Pam also welcomed Trustees Margaret Wright Vice Chair & Project Manager, and Lynne Boyle Membership Secretary.

Pam thanked Phil Corr for the raffle (raised £50), Ann Sadler for the biscuits and Carol Suffell for her administration assistance.

Pam advised that Area 1 was awarded £300 from the Middlesbrough and Teesside Philanthropic Foundation for running costs. Many thanks to them.

The Carrot Walk, which Kate Gilbert Chair and Jennifer Nott Trustee of PMRGCAuk entered and completed, raised £3,000 in sponsorship. This will be matched £1 for £1 by Fight For Sight who organised this walk. The £6,000 is for Research into GCA.

Pam introduced Harry Simpson, personal trainer, to a full room. He gave a talk on the benefits of gentle exercise and how it improves physical and mental health. He had plenty of tips for the group and they joined in some light exercises with Harry. Everyone enjoyed it.

Harry Simpson and Members.



Harry also mentioned the benefits of Nordic Walking and gave a demonstration. Harry explained that this type of exercise was suitable for PMR sufferers and Stroke victims.

Pam thanked Harry for his informative talk and advised that she had contacted Age UK, and a list of venues and times for classes of Nordic walking is available on request. A new class in the Redcar area will soon be set up and she will pass on details when known. The cost is £15 for 6 sessions.

Shirley O'Connell's experience of Nordic walking is also available on request.

Middlesbrough New Year lunch and next meeting

Wednesday 16 January 2013
12.30pm – Lunch
1.30pm – Meeting

Marion Country Club

Please contact Pam on 01287 623334 or email if you would like to attend the lunch before the meeting. We must give final numbers by 11 January 2013.

Gateshead Area 2 News

September

It was a dreadful day on Monday 24 September, so we were surprised and delighted that so many people battled the elements and attended the meeting.



Amy Duguid (Senior Physiotherapist) from the Rheumatology Department Queen Elizabeth Hospital, Gateshead was the guest speaker. Amy explained that exercise reduces joint pain and stiffness, builds strong muscle around the joints and increases flexibility and endurance. It also reduces the risk of other chronic conditions, improves sleep, helps weight loss, decreases depression and increases self-esteem.

Amy talked about low-impact exercises such as swimming, walking and riding a stationary bicycle, and explained they burn calories but do not place excess strain on the muscles and joints. In addition to their calorie-burning benefits, low-impact exercises can improve overall well-being and reduce stress.

Polymyalgia Rheumatica causes your muscles to become tense and may affect your ability to move and is worsened by inactivity. Failing to stretch your muscles can cause them to become reconditioned which leads to more pain and weakness,



therefore it is beneficial to incorporate stretching episodes of between 3 and 5 minutes three times a day into your exercise routine. Amy demonstrated these exercises. Pace yourself by starting gentle stretching exercises and slowly building up to 30 minutes of exercise most days of the week. Examples of these exercises will be available at our next meeting.

Amy concluded her talk by asking members to take part in short exercises with a five-minute Tai Chi exercise. We thanked Amy for a wonderful talk and demonstration and she said she would be delighted to come back again.

Gateshead meetings 2013

All on a Monday at 1.30pm
Wailles Room, Gateshead Library, Prince Consort Road, Gateshead

28 January: Post Christmas Buffet
Social occasion. Family, Friends and Carers welcomed. £5 a head, inclusive of wine and soft drinks.

25 March
Guest Speaker: Helen Long, Dietician – Cookery Demonstration.

24 June
Guest Speaker: To be advised.

29 September
Guest Speaker: Dr V Saravanan, Consultant Rheumatologist and Patron of PMR & GCA UK North East Support.

Age Scotland Awards 2012

Jean Miller PMR-GCA Scotland was awarded the Jess Barrow Award



Jean Miller

The Age Scotland Awards are a platform to celebrate those in Scotland who have made a significant difference to improving the lives of older people. This year, the Awards were made at the Age Scotland Annual General Meeting and Awards Ceremony on 14 November 2012 at the City Chambers, Edinburgh.

- Jess Barrow Award for Campaigning
- Patrick Brooks Award for Partnership Working

The Jess Barrow Award is given to an individual or group whose campaigning has highlighted specific issues and effected change to the benefit of older people.

Jean set up Tayside PMR & GCA Support in March 2006 after having suffered PMR and GCA for over four years. In March 2008, Jean was one of the group of 25 people who attended a landmark meeting with Professor B Dasgupta in London. Jean was a driving force in setting up not only her Scottish Charity PMR-GCA Scotland, but the National Charity PMRGCAuk as well.

We are so pleased that Jean's untiring dedication and campaigning on behalf of PMR and GCA has been recognised in Scotland.

PMR GCA uk: Surrey Support Group



Shirley

From little acorns...

It all started at a PMR and GCA patients' research meeting in Spring 2011 led by my consultant rheumatologist, during which a lady who had previously run a small support group in the South of England under the auspices of the National Organisation, PMRGCAuk, gave a talk on setting up and running a support group.

Following this meeting, and as a sufferer of both PMR and GCA, I looked back and thought about the wonderful support I had received at the outset of my illness from the leaders of long-established support groups in East Anglia and in the North East of England. It was the motivation I needed to offer my support to other new sufferers in the way I had been supported and, together with another member who produces our newsletters, and with help from the rheumatology researcher at our local hospital, PMRGCAuk Surrey Support Group was born.

Surrey's first meeting took place in July 2011 at a local Inn, and 12 people from Surrey and surrounding counties enjoyed a very friendly get-together, sharing their personal experiences of living with PMR and/or GCA. We have since had several further meetings at a hired Council venue where, with the help of our local hospital rheumatology researcher, we are able to enjoy talks by various guest speakers. These have included a consultant rheumatologist, a physiotherapist, and a consultant ophthalmologist. Surrey now has 41 registered members, plus several other contacts, some of whom travel from quite distant parts of the country, with one amazing lady travelling from as far afield as South Wales.

Between organising the meetings and answering telephone and email enquiries, I never have a dull moment but it is so rewarding to hear the relief in someone's voice on the telephone when they realise for the first time that they are no longer suffering alone with this debilitating and painful condition.

Shirley – Chair, Surrey Support Group November 2012



Introducing **Christine Beet** a new Trustee and PMR&GCA UK North East Support Interactive Forum pmrandgca.forumup.co.uk

This interactive forum gives you an opportunity to make new friends and chat about Polymyalgia Rheumatica and Giant Cell Arteritis.

This forum was initially started as a trial for three months to see if people would be interested.

It took off and grew like topsy. So the trial was more than successful. We looked at the situation and decided that we did not want to lose this forum and felt it needed to be on a firmer footing. The National Charity PMRGCA uk has joined Facebook, Twitter and Health Unlocked.

We asked Christine Beet, who together with Pam Hildreth had initially set up the forum, to become a Trustee of PMR&GCA UK North East Support. Christine accepted the invitation. Christine administrates the interactive forum, which is specifically for PMR & GCA patients.

I live in Central France with my husband Dave and two Bichon Frisé dogs, Sparky and Monty.

The language barrier caused a bit of difficulty with the diagnosis of my PMR two years ago but, with the aid of leaflets and papers I printed off the Internet and translated for my GP, we eventually got there!

I was 58 years old when the symptoms began and I felt truly lost with no one to discuss things with and no one to understand what I was going through. On the day I discovered the NE Support Group I cried for hours with the relief of being able to share my problems.

I began to think about others like me, even those in the UK who cannot attend a support group. I have run an online forum for Bichon owners for several years, as well as another local forum for expats, and I know how helpful and supportive they have been and what friendships have been forged.

I then suggested to Pam Hildreth that all PMR & GCA patients would benefit from an interactive forum! I think the rest is probably history!

The PMR & GCA UK North East Support Group interactive Forum began in March 2011. We now have 550 members and in the short time the forum has been in existence almost 40,000 messages have been posted. Some of these have been media and research reports or information about PMR and GCA – others are items of general interest and even photos from members. All of the posts are of interest to someone and it is fair to say that the forum has been a success. It certainly allows our members and their families a broader view of PMR and GCA with the many personal accounts. Every day there is something new on there and due to the fact that we have members all over the world now, in most time zones, there is usually someone to listen to your thoughts whatever time of the day (or night) you want to log on and chat! I am very proud to be more closely associated with the NE Group in my new role and hope I can make a useful contribution!

I certainly have made many new friends due to PMR, so it can't be all bad can it!

An Unwelcome Guest

We didn't ask to have it
We want it to go away
But it doesn't matter how hard we try
It seems to want to stay

We said it wasn't welcome
An uninvited guest
It just keeps niggling away at us
Its such a flippin' pest

It hurts when we sit down
And even when we stand
No wonder we get cross with it
But it doesn't understand

Just leave us all alone
You're not welcome any more
We want to have our lives back
You're becoming a real big bore

There's some relief from our old friend
The loved and hated Pred
Perhaps they'll find a cure
But we won't be holding our breath

We've come to the conclusion
It only gets the best
So b*gger off, just go away
We're tired and need a rest

But here's to those who've beaten it
PMR and GCA
Wouldn't it be great if we could
Just throw them both away!

By **Lizzie Ellen** 6 February 2012.

Lizzie has PMR and is a member of the Surrey Support Group and posted this on the forum.

Raising funds

We **DON'T** want you to do this –
Greenhouse made out of CD & DVD cases
– we **WANT** them with the contents

As you are all aware, we are constantly raising funds for our Charity PMR&GCA UK North East Support to help with our running costs (our hall hire has gone up £20 to £70 a meeting, postage has increased twice this year). We have negotiated with an organisation to recycle all these items for cash for our charity. Our last collection raised over £50. So please have a good clear out, and ask your friends to help and bring to our meetings your unwanted CDs, DVDs and computer games to help us help you.

All CDs & DVDs must be in good condition, not scratched or boxes cracked and **MUST** show a bar code. Albums only please, no singles, and they must not be copies or from free newspaper promotions



FOR SALE: Pansy Badges

We have Pansy Badges for sale, why not buy some to pop into your Christmas presents.

The pin badge/tie pin cost just **£1** each

If you order by post, sorry but we will have to charge an extra 50p for the 1st badge (£1.50) and £1 for each extra one you order which will be in the same package.

For an extra **25p**, why not buy a gift bag for your pansy badge (no extra charge for postage).



PMR&GCA UK North East Support Donations & Gift Aid

We wish to thank all the people who have donated monies to us over the past few months. We also wish to thank those taxpayers who filled in **Gift Aid** forms.

Gift Aid enables us to claim **25p** for every **£1** donated from HMRC. Once you fill in a **Gift Aid form** we can claim without you ever having to fill in another form.

Further information on our website:
www.pmr-gca-northeast.org.uk



So what's an Acid Reflux (Heartburn) sufferer to do?



Fortunately there are effective, natural alternatives. You can supplement with a good digestive enzyme formula to reduce the need for stomach acid. Take a teaspoon of apple cider vinegar mixed with water and a little honey at each meal. Drink less with your meals. Fluids dilute stomach acid, which triggers the stomach to produce more to compensate. Eat less at one time. This allows the body to digest a meal with lower levels of stomach acid needed, or take the juice of one lemon, divided into three, add to a glass of water three times a day. If you put the lemon in the microwave for one minute – twice as much juice.

Apply for a **Blue Disabled Badge** if walking is a problem (less than two car lengths, you have a problem).

You may be entitled to an **Attendance Allowance**. You may no longer be able to clean your house, do your garden, go shopping, drive your car, then have to take a taxi for hospital, GP appointments and shopping.

Contact your Council and ask for **Adult Social Care**, if you need equipment such as showers, perching stools, raised beds, chairs, or for any other assistance.

Ask your GP for a **Vitamin D deficiency test**, this should be done prior to diagnosis. Vit D deficiency causes aches and pains just like PMR. Calichews will not make up the deficiency. They work once the level is correct.

Ensure you have a **Dexa scan** once you have been on prednisolone for six months.

Stick to **ONE pharmacy** (one branch, if a multiple). The pharmacist should be a back-up, so any other medication prescribed, or you want to buy over the counter or from a health shop, can be checked for compatibility.

Published by PMR&GCA UK North East Support
Designed by GDA (www.gda-design.co.uk)
Printed by Statex Colour Print

Registered Charity No: 1138409

Prednisolone – a soluble 5 mg tablet is available for those who get tummy probs or have difficulty swallowing tablets.

When you wake up, take your pred with a cuppa and something to eat even if it is 5am. Then snuggle down for an hour or so and give it time to work. This helps the stiffness in the morning. A hot shower on getting up helps.

Whilst taking enteric-coated prednisolone you may develop a rash on your body – particularly on the head. Gently rinse the coloured coating off the prednisolone before taking. It can cause allergies.

Reducing Pred. Look on your calendar and decide which day you are going to take a drop. Then ensure you have as little as possible to do for the next four or five days. If you are going to be busy, choose another day to start the drop. If aches and pains start, wait it out for four or five days. If the pain subsides, it was steroid withdrawal pains. If they do not subside, it is too soon go back to the dose you were on and stay there for a while, then try again.

Calcium tablets – Prednisolone for breakfast – Calcium at lunchtime. Never the two together, the prednisolone stops you from absorbing the Calcium.

Remember the **ESR** and **CRP** are guidelines. Steroid dose adjustment should not be done solely on the basis of blood tests.

GP's appointments. These are for 10 minutes at a time. Sometimes you know you need longer. Most practices will book a double appointment. This stops you feeling that you must get in and out as the next person is waiting.

Some GPs will allow you to ring and get the results of your last blood tests without the need for an appointment. Ask, it helps them and you to cut out unnecessary visits. Ensure you keep a record of the results.

GCA patients are entitled to two **free eye examinations** yearly. Your optician has a specific form to fill in for the NHS.

Methodextrate – always take it last thing at night, patients taking it have found that it does not make you feel so sickly.

Finally, try a **'Duvet Sandwich'** for comfort at night.

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We would also like to thank all our members, their families and friends for their kind donations.