

# PMRGCAUK

POLYMYALGIA RHEUMATICA & GIANT CELL ARTERITIS UK

Newsletter 

Issue 4  Autumn/Winter 2011

## Warm welcome to our new members

PMRGCAuk would like to thank our recently joined members for showing such interest in helping the national charity grow. Of course, anybody can benefit from the work of the charity, but our members are crucial in supporting our work, most of which is completely voluntary. We can proudly say that PMRGCAuk has 214 fully-voting members (beginning of November 2011) with optimistic prospects to keep expanding. We are also gaining attention in our Facebook page that will soon hit the 100 'likes'. And of course, there are the many hundreds of local and regional members of affiliated support groups all around the country.

### Moving around the library

Because of restructuring plans at the Central Library our office has moved now to the second floor.

Birmingham Arthritis Resource Centre (BARC) is still hosting this charity in a larger and more comfortable space. We have also



*Birmingham Central Library, our home for the next two years*

set up a contact number for general enquiries and information: **0300 999 5090**.

### What did you do for World Arthritis Day?

PMRGCAuk joined BARC at the Birmingham Central Library to mark World Arthritis Day on 12<sup>th</sup> October. The idea was to approach general public to raise awareness on musculoskeletal diseases such as PMR and GCA and talk about the risks that a late diagnosis or neglected symptoms may cause. Birmingham residents were also given information on the benefits that a healthy diet and a physical routine can do for sufferers and non-sufferers.

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## PMRGCAuk needs you!

As we grow, we are finding more and more ways to reach out to people with PMR and GCA, but there is always more and more to do! Could you find a few hours a month to help us and other people with these conditions? There are plenty of opportunities, even if you are more or less housebound! Ways in which we would like to involve volunteers include:

- Being at the end of the 0300 helpline. Do you have counselling experience? Or would you be interested in training to listen to people on your phone (we transfer the calls automatically)
- Befriending someone in a 'buddy' system to chat with them occasionally on the phone or meet up for a coffee
- Helping organise events
- Writing and editing items for the newsletter
- Helping with fundraising
- Being an 'expert patient' speaking with professionals and researchers

If you would like to get involved please drop us a line, or phone **0300 999 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

# Why is PMR hard for GPs to diagnose?

**Dr. Louise Warburton**, specialist GP in Rheumatology and Musculoskeletal medicine, explains that Polymyalgia Rheumatica (PMR) is relatively rare. About one in every 1200 people will develop PMR and a fifth of those will go on to develop temporal arteritis.

The symptoms of PMR are relatively non-specific and this makes it harder to diagnose. The symptoms can mimic those of osteoarthritis, depression, gout or rheumatoid arthritis. Where the symptoms are well defined and of sudden onset, it is easier to make a diagnosis. The most reliable blood test is the Erythrocyte Sedimentation Rate (ESR). In PMR this will be raised and sometimes is very high. The normal range for

ESR is up to twenty, but some patients with PMR will have an ESR of 100.

However, lots of other diseases can cause a raised ESR; serious infections, cancer, and rheumatoid arthritis can all give patients a raised ESR. The other confusing feature of PMR is that it can co-exist with other serious conditions such as malignancy. So the diagnosis may be delayed whilst the GP looks for other hidden problems, by performing investigations such as a chest X ray.

In both PMR and GCA, the response to steroids is supposed to be classical; the patient will feel remarkably well and cured within a few days of starting the steroids.

When this happens, it gives strength to the diagnosis of PMR. Unfortunately, some patients with other conditions such as Rheumatoid or Osteoarthritis will feel better on high dose steroids and the GP and patient are then lulled into a false sense of security and think that they have a secure diagnosis of PMR. The error only becomes obvious when the patient begins to reduce their dose of steroids and the symptoms re-appear.

Sometimes, the GP will refer their patient to a consultant for a specialist opinion about whether they have PMR or not. Even the Rheumatology Specialists can have difficulty with the diagnosis and it is then a matter of 'trial and error'.

*See our profile of Louise on page 6*



*PMR symptoms can mimic those of osteoarthritis, depression, gout or rheumatoid arthritis. Symptoms consist of aching in the shoulders and thighs, tiredness and stiffness.*

## Edgar Stene Essay Prize

Do you love writing? Every year EULAR, the European League Against Rheumatism, holds an essay competition. Closing date is 31 Dec 2011 for a 2-page A4 essay on "Overcoming the challenges of getting around with a rheumatic or musculoskeletal disease".

Contact us for more details!



Follow us on Facebook!

**PMRGCAuk**

Visit our website for the latest news in PMR & GCA: [www.pmrgcauk.com](http://www.pmrgcauk.com)



# South East & South Coast

## Surrey Support Group

**Shirley.** I was finally diagnosed with both PMR and GCA in March 2007 after having spent many months of the previous year confined to bed unable to move a muscle without excruciating pain, attending hospital appointments by ambulance and wheelchair. Although the eventual diagnosis and commencement of steroid treatment gave me rapid relief of



Shirley O'Connell wearing a PMR/GCA UK shirt

the worst of my symptoms, I had never heard of either illness and felt confused and alone.

I made contact with Jennifer Nott who also had PMR

and runs a support group in Suffolk. I remember feeling so elated after talking to someone who understood from experience what it is like to live with an illness that takes over your life. Jennifer referred me to an internet forum ([www.experience.patient.co.uk](http://www.experience.patient.co.uk)) where I found people who had banded together to support each other – my feeling of isolation lifted immediately.

In April I attended a patients' meeting arranged by consultant rheumatologist, Dr Rod Hughes, at St Peter's Hospital in Chertsey, aimed at imparting information about the diseases; helping to set out a patient-driven research agenda to discover which symptoms cause most distress; and an opportunity to consider whether West Surrey needed a patient support group. Jean Lymer, who has provided

individual support to people in the South East region for several years, also spoke at this first meeting. Here was the motivation I needed to offer my support to other new sufferers in the way I had been supported, and, with help from Margaret Walsh, researcher at St Peter's Hospital, PMR/GCA UK Surrey Support Group was born.

Twelve people from Surrey and Sussex met in July, in Chertsey. We enjoyed a very friendly chat and shared our personal experiences on symptoms, response to medications and steroid tapering regimes.

Dr Rod Hughes has very kindly offered to talk at our next meeting on 8<sup>th</sup> November at St Peter's Hospital about steroids and

gained a number of other medical conditions over the years, some steroid induced, some not, but have also gained a lot of experience and knowledge about PMR & GCA and steroids.

I had been wanting to start up a Support Group for some time. Meeting up with Chris provided the opportunity I had been looking for and during the summer months we have got all the technicalities sorted for running our group.

**Chris.** I was diagnosed with PMR in January 2005 and subsequently in December 2010 I was diagnosed with atypical GCA via a PET scan (no temporal artery involvement, same as Catie).

We have both been on

Methotrexate and Chris on Azathioprine as steroid sparing agents. We are happy to share all our experiences and try to help those who are recently diagnosed – there still seems to be little support or back up for those who will almost certainly be on steroids

long-term and the number of very frightened people we have spoken to is worrying.

We have found it quite hard to get going, and we have realised that this is an area where not many sufferers are computer literate. Most rely on telephone support, which we are happy to provide and we are hoping that in the next few months we can establish a group more firmly in this area.

To join Shirley in Surrey, or Catie and Chris in West Sussex, please contact us on 0300 999 5090



PMR/GCA UK Surrey Support Group gathering

accompanying medications and their side effects on the endocrine system. The meeting is already expected to attract double the number of previous attendees which really does prove that Surrey was, without doubt, in need of a support group.

## West Sussex & Brighton Support Group

**Catie.** I was diagnosed with PMR in January 2002 (GCA followed with an atypical presentation in 2006) and next year I will have been taking steroids for 10 years. I have

# Latest research studies in PMR & GCA

Lately, rheumatologists, other professionals and even the pharmaceutical companies have been getting more interested in PMR and GCA. Here is a round-up of some of the research studies that are taking place around the country.

## Diagnosis

### Temporal Artery Biopsy vs. Ultrasound (TABUL)

#### Purpose: To improve accurate diagnosis in GCA

The Temporal Artery Biopsy -v- Ultrasound in diagnosis of Giant Cell Arteritis (TABUL) study is being led by Prof. Raashid Luqmani at the Nuffield Orthopaedic Centre in Oxford. This NIHR (National Institute of Health Research) portfolio adopted study has been designed to investigate the specificity and sensitivity of temporal artery biopsy compared to ultrasound for the diagnosis of Giant Cell Arteritis (GCA). The study is funded by the NIHR Health Technology Assessment (HTA, Reference Number HTA Project 08/64/01).

GCA causes inflammation and narrowing of blood vessels, and can cause blindness in one third of patients. It is highly important that a prompt, accurate diagnosis of GCA is made and a steroids treatment is given for two or more years. Temporal Artery Biopsy (TAB) is the current 'gold-standard' but imperfect test for diagnosis of GCA.

The patient will have a biopsy of a temporal artery (a minor procedure performed under local anaesthetic to remove a sample of one of the scalp arteries), however, around 4 out of 10 patients will have a normal falsely negative result which will provide an imprecise diagnosis.

As part of the TABUL study, an

ultrasound scan of the arteries in the side of the head and under the arms will be performed before the patient go for their TAB. Ultrasound seems to be useful in the identification of GCA and does not involve surgery; the test can be performed as an outpatient. The TABUL study will compare the temporal artery ultrasound to temporal artery biopsy, and aims to discover whether ultrasound is as reliable as biopsy, whether it is as acceptable to patients, and whether it is cost effective.

The researchers aim to have 430 patients involved in the study. There are around 25-30 hospitals that have signed up to this study with patients enrolled in hospitals located in Oxford, Southend and

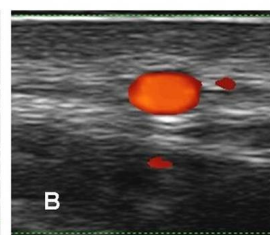
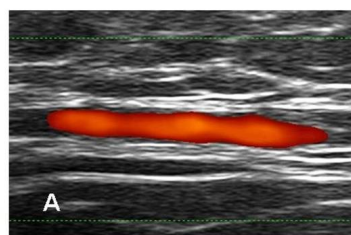
Stoke Mandeville to date. So far the study has reached approximately 40% of the target enrollment.

Patients can only be recruited into this study when they are first suspected of having GCA, and they must not have had steroids recently for any reason apart from PMR. They will receive an initial clinical assessment, blood tests, ultrasound and biopsy within 7 days of starting high dose steroid treatment. The study includes three visits (baseline, after 2 weeks and at 6 months) and otherwise patients are seen in the normal clinic as required. Further information on: <http://www.ndorms.ox.ac.uk/clinicaltrials.php?trial=tabul>

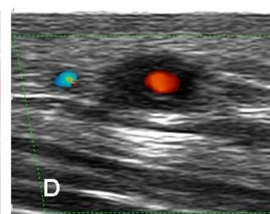
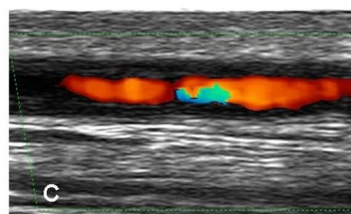
### Ultrasound Scans

Longitudinal scan

Transverse scan



A and B  
Normal Temporal Artery



C and D  
'Halo' sign in GCA

# Treatment

## Novartis study – PMR

### Purpose: To assess the efficacy of two new drugs for PMR

This study will test two new drugs: canakinumab and AIN457. They may block chemicals in the body which are thought to be involved in PMR. The study aims that using these drugs at the beginning of disease will lead to fewer flare ups and lower overall doses of steroid needing to be used in the long term. Patients will be recruited at their

first diagnosis of PMR, and this must be before they receive any steroid treatment. They will be chosen randomly to receive a single dose of one of these two test drugs for a period of two weeks, and will also receive steroids. Patients will be followed up for 6 months in the study.

## Lodotra (delayed release prednisolone) in GCA

### Purpose: To tackle inflammation at most appropriate time

Morning stiffness is one of the most frequent symptoms in inflammatory diseases. This is because it has been found that the chemicals involved in inflammation are at their highest level at about 4 am. This can be avoided with prednisolone administered two hours earlier but this is inconvenient for most people.

Lodotra, a modified-release form of prednisolone, is a new version where the drug is contained in a slow release tablet which breaks down to release the prednisolone at about 2-3 am in the morning. Therefore, the prednisolone

should 'hit' the inflammation at the most appropriate time of day. Lodotra has shown to be effective in rheumatoid arthritis, and also because the prednisolone is available at the key time, lower doses are needed.

Southend Hospital is planning to set up a small-scale 6-month pilot study to see whether this concept works in GCA as well. It aims to recruit 30 patients from 2 or 3 hospitals. If it is successful, a wider scale study would be planned.

## Leflunomide in GCA

### Purpose: Use of the drug for treating uncontrolled PMR or GCA

Sometimes PMR and GCA do not respond to steroids alone. Leflunomide is an alternative drug commonly used as an anti-rheumatic drug in rheumatoid arthritis. It is showing promise in patients with PMR and GCA who are having trouble reducing the dose of steroids because of relapses.

A number of leading UK rheumatologists have put an application into Arthritis Research UK for funding towards a large study of leflunomide in GCA. This is currently going through Arthritis Research UK's review and approval process.

*This is a selection of a number of research projects. In our next Newsletter, we will be profiling a newly-launched project at Keele University, looking into the experiences of newly-diagnosed PMR patients, particularly in relation to diagnosis and early treatment by their GPs.*

## Blood Test

Currently, several studies looking at blood samples are being carried out as blood tests have been used for the diagnosis of PMR and GCA. Although no blood test is 100% reliable for diagnosis of either conditions. Researchers are looking at substances in the blood that may be implicated in the development of inflammation in PMR and GCA, and also possible underlying genes.

For instance, there is a chemical in the blood called Annexin which is seen in high levels in people with inflammatory conditions, but seems to be found in ever higher levels in PMR and GCA. Experts think this is a reliable finding and then Annexin could be a useful target for the development of new drugs. This can also be useful for the diagnosis and monitoring of these conditions.

## Biobank

Several studies in GCA and PMR are also asking patients whether they would be happy to supply samples to be kept in a biobank. This is to build up an anonymous 'library' of blood samples and temporal artery samples.

The concept of a Biobank will help researchers to access to samples more rapidly. Therefore, whenever in the future other studies are set up looking at chemicals in the blood, these samples could be available to use.

# Dr. Louise Warburton

## Profile



Louise Warburton has worked as a GP for twenty years and started working in a Rheumatology Clinic nineteen years ago, as a clinical assistant. Initially she worked just once a week in the specialist clinic and was a partner in a GP practice in Shropshire.

Recently, the Clinic lost its local Consultant Rheumatologist who moved on to pastures new, and there was a need for someone to fill the gap. Dr. Warburton had already done extra training in musculoskeletal medicine, obtaining a Diploma in Musculoskeletal Medicine after three years of post-graduate study. She therefore began working less in general practice and more in the MSK and Rheumatology Services.

The team was successful in establishing a Community Rheumatology Service in Telford and Louise now works there half time and spend some time in the MSK service as well. The service has now recruited two new Rheumatologists.

Currently Dr. Louise Warburton is President of the Primary Care Rheumatology Society and a trustee of the Arthritis and Musculoskeletal Alliance (ARMA). She thinks that these two positions “allow me to have real influence on National Issues of Musculoskeletal Health.”



## Jargon Buster

### ‘Steroid-sparing’ medication?

As we all know, corticosteroids (prednisolone) are the standard treatment for PMR and GCA. But what happens when someone has a bad reaction to prednisolone, or after a long time on steroids they are finding that they can’t reduce their dose to a reasonable level, even with the ‘help’ of painkillers? Sometimes, in these more complicated cases, doctors will try a ‘steroid-sparing’ medication. The most commonly used drug in this category is methotrexate, though trials are beginning with leflunomide.

Methotrexate is a powerful drug that readers may have heard of in connection with chemotherapy for cancer treatment. It has also been found to have anti-inflammatory properties, and has been used for some time in the control of rheumatoid arthritis. Now, doctors are trying it out in cases of PMR and GCA, but so far the evidence is inconclusive. Methotrexate may enable the steroid dose to be reduced, rather than substituting for prednisolone altogether.

There are conflicting messages from randomised controlled trials of methotrexate as a steroid sparing agent in GCA. In a Spanish trial in 42 patients over 96 months, adding methotrexate 10mg weekly to prednisolone was more effective in controlling disease activity than prednisolone alone, with fewer relapses and lower cumulative steroid doses. MTX has to be administered in low doses as it is a very toxic substance. So some GCA and/or PMR sufferers who have tried methotrexate have found that they simply can’t get on with it, whereas others have found that it has really helped them to reduce the level of steroids they have to take to keep their pain and stiffness under control.

Leflunomide is another potent medication that may show some promise for sparing the overall amount of steroid a patient has to take in a ‘complicated’ case. A strong immunosuppressant, it is a ‘disease-modifying anti-rheumatic drug’ that has been used to slow down the progression of rheumatoid arthritis. It works by suppressing the body’s manufacture of a chemical compound known as pyrimidine. To date there is very little research evidence of its action in cases of PMR and/or GCA, but a proposal is currently under consideration to carry out trials – see our research feature in this issue.

# PMRGCAuk is growing!

We want to welcome our new Support Groups at West Sussex/Brighton and London. Hopefully we will be soon announcing a new Support Group in Birmingham. Contact us to get involved! We would love to hear from you.

## Eastern England

### PMR-GCA Support East Anglia

**Jennifer Nott** - Tel.: 01449 720 545

or

**John Parsell** - Tel.: 01449 672 592

Email: eastanglia@pmrgcauk.com

## Southend/Essex

**Hannah Padbury** - Tel.: 01702 587 436

Email: southend@pmrgcauk.com

## South West England

### South West Support Group

**Wendy Morrison** - Tel.: 01823 663 911

Email: southwest@pmrgcauk.com

or

**Sue Halliday (Bristol area)** - Tel.: 07501137887

Email: bristol@pmrgcauk.com

or

### Wiltshire Foggy's

**Deb Davis** - Tel.: 0844 887 2377

Email: swindon@pmrgcauk.com

## Southern England

### East Sussex/Kent

**Jean Lymer** - Tel.: 01403 732 981

Email: eastsussex@pmrgcauk.com

### West Sussex/ Brighton

**Christine Young &**

**Catherine Pickersgill**

Tel.: 0300 111 5090

Email: westsussex@pmrgcauk.com

## Surrey

**Shirley O'Connell**

Email: surrey@pmrgcauk.com

## Greater London

### London (In preparation)

**Lesley Dean & Laurene Brooks**

Tel.: 0300 111 5090

Email: london@pmrgcauk.com

## Midlands

### Peterborough

**Gillian Green** - Tel.: 01733 700 110

Email: peterboro@pmrgcauk.com

## North East

### PMR & GC UK North East Support

**Pam Hildreth** (Middlesbrough, South Durham, Teeside)

- Tel.: 0300 111 5090

**Mavis Smith** (Tyne & Wear, Northumberland, North

Durham) - Tel.: 01914 111 138

Email: pmrgcafightersne@googlemail.com

Web: [www.pmr-gca-northeast.org.uk](http://www.pmr-gca-northeast.org.uk)

## Wales

### Wales PMR-GCA Support

**Glyn Hughes** - Tel.: 01633 483 186

Email: wales@pmrgcauk.com

## Scotland

### PMR-GCA Scotland

**Jean Miller** - Tel.: 01382 562 974 or

**Alison Jeffrey** - Tel.: 01334 870 674

Email: info.scotland@pmrandgca.org.uk

Web: [www.pmrandgca.org.uk](http://www.pmrandgca.org.uk)

## Not yet a member?

Become a member today and you will be supporting a UK charity dedicated to improving support to PMR & GCA sufferers, raising awareness within the medical world and general public, as well as promoting research into both conditions.

Call us on **0300 999 5090** (office) or email [pmrgca@gmail.com](mailto:pmrgca@gmail.com)

or visit our website: [www.pmrgcauk.com](http://www.pmrgcauk.com)

Whether or not you have joined, our helpline is here to listen on 0300 111 5090

# Fundraising events - News @ PMRGCAuk

## Thank you Chloe!!

9-year old Chloe Bonnick, member of the 15th Chingford Scout Group, organised a sponsored walk to raise money for PMRGCAuk. Chloe's grandfather John is a PMR sufferer and she was so very upset to see him in such pain that she felt she had to do something to help. Chloe persuaded her cub scout troop to join her and in June they each walked 3 miles and together raised £400. PMRGCAuk Trustee Director Dorothy Byrne collected the cheque on behalf of the charity.



## Meeting at Southend in April 2012

The Southend and South East Essex Support Group is holding a meeting next spring at Crowstone Christian Centre in Westcliff-on-Sea on Tuesday 3<sup>rd</sup> April from 2pm to 4pm. Support Group organiser Hannah Padbury announced that the group has invited Billy Fashanu, Senior Physiotherapist at Southend. His talk will be on exercise and mobility for PMR and/or GCA sufferers. For information, please call on 01702 587436 or email [apadbury@toucansurf.com](mailto:apadbury@toucansurf.com)

## Join the Virtual Support Forum online!

If you want to know more about PMR & GCA, share your experience or just have a look, visit this link and register:

<http://pmrandgca.forumup.co.uk>



## PMR-GCA Support East Anglia Autumn Meeting

The East Anglia Group held their Autumn Meeting in Suffolk on 19<sup>th</sup> October. The event had a record attendance of over 100 people who arrived to enjoy comparing notes with each other over refreshments. Leading medical authority Prof. Baskar Dasgupta led the talk about the raising of awareness particularly amongst GPs over the diagnosis and management of PMR and GCA. He spoke about patient self-management, particularly in the context of steroid reduction, and of continued medical research into possible alternatives to steroid treatment. In the case of GCA he stressed concern over possible visual loss caused by delayed diagnosis and treatment of GCA and the part he is playing in investigating patients' cases.



## Booklet release & Winter Meeting @ Peterborough

Peterborough Support Group organiser Gillian Green together with Chair of group Clare Marshall have released a booklet called "In A Moment The Sun Goes Down." This offers a personal story on what it is like living with such a debilitating condition as PMR and GCA can be.

Email [green.gillian1@sky.com](mailto:green.gillian1@sky.com) or ring on 01733700110 to obtain a copy for £3.50 + 50p postage. By buying the booklet you will contribute with 50p to Peterborough Support Group Funds. The group is organising a **Winter Meeting** on the 25th November with a consultant rheumatologist giving a presentation at 1st floor Conference room, City Care Centre, Thorpe Road at 2.15pm to 4.45pm. Please contact Gillian if you want to attend.

