

### A welcome from the Chair....

Welcome to the second PMRGCAuk newsletter. It contains lots of information about what we have been doing over the last six months, from our official launch at the Wellcome Foundation, in April, to the publication this month of our strategy for the next three years.

It was a proud moment to be appointed by the Trustees to be Chair of this very new and much-needed organisation. We have a really good team of Trustees, and now we need to grow our membership 'on the ground' and build the network of support groups around the country. We have a long way to go, but we are determined to make a real difference to the many thousands of people in the UK who are diagnosed each year with polymyalgia rheumatica and/or Giant Cell Arteritis. Most of all, we want to contribute to preventing those estimated 1000 or so tragic cases each year of people who lose their sight completely, and completely unnecessarily, through late diagnosis of GCA.

When the first newsletter was published

to coincide with the launch, there was lots of excitement about the fulfilment of two years' hard work. We got a bit carried away with our enthusiasm, and one statement was exaggerated. We said that PMRGCAuk charity was 'the first in the world' specifically dedicated to PMR and GCA. This was overlooking established charities in the Netherlands and the US, but particularly, the UK's own PMR-GCA Tayside (now PMR-GCA Scotland), founded by Jean Miller, which achieved charitable status in 2007. We are sorry that we gave a false impression. There have also been groups established for some time, on a local and regional basis, and over the next few newsletters we will be having a special regional 'Focus' slot. We start this issue with East Anglia.

Hoping you enjoy this, your newsletter, Wishing you good health and well-being

Kate Gilbert

### Inside this issue.....

WELCOME	1
PMR & GCA HIT THE NEWS	1
NATIONAL LAUNCH	2
NE DVD LAUNCH	2
THOSE LITTLE RED PILLS	3
CLACIFICATION CRITERIA FOR PMR	3
FOCUS ON EAST ANGLIA	4
SOUTH-WEST	5
PMR GCA SCOT-	5
PROFILE PROF. BHASKAR DASGUPTA	6
JARGON BUSTER	6
THANKS	7
CONTACT NATIONAL HELP	7
BECOME A MEMBER!	7
MEMBERSHIP FORM	8

PMRGCAUK IS A REGISTERED CHARITY ESTABLISHED TO MEET THE NEEDS OF PEOPLE WITH THESE DEBILITATING CONDITIONS BY RAISING AWARENESS, PROMOTING RESEARCH AND OFFERING SUPPORT

### PMR and GCA hit the news!

In recent months we have seen a growth in media interest in both polymyalgia Rheumatica and Giant Cell Arteritis. Several people in the public eye who are living with these conditions have helped to publicise them and raise awareness. They include Lady Wendy Levene, Dorothy Byrne of Channel 4, and Babs Powell, who many people will remember fondly from her days as a member of Pan's People, the dance group on Top of the Pops. Babs' experience of PMR and GCA has been highlighted in the Daily Mail online at:

[www.dailymail.co.uk/health/article-1335727/Pains-People-Former-TV-dancer-Babs-Powell-suffers-debilitating-arthritic-condition-caused-strenuous-career.html](http://www.dailymail.co.uk/health/article-1335727/Pains-People-Former-TV-dancer-Babs-Powell-suffers-debilitating-arthritic-condition-caused-strenuous-career.html)



## The 'National' launches at the Welcome Trust

April 2010 saw the official launch of the new UK-wide charity, PMRGCAuk



The event was opened by Wendy welcoming everyone and painting the picture of how we formed and there were excellent talks by Professor Dasgupta about his work and hopes for the future, Kate Gilbert about living with PMR and Jennifer Nott from East Anglia Support Group about support groups and finally John Gibson about the need for fund raising.

Also in attendance was Dorothy Byrne who works for Channel 4 TV and at only 50 yrs old suffers from PMR and GCA. She has joined us and has already penned two wonderful articles which appeared in the Daily Mail during March and April. Dorothy is set to "shout it from the Rooftops" :-

<http://www.dailymail.co.uk/health/article-1262172/Wendy-thought-muscle-aches-signsageing-fact-days-going-blind.html>  
<http://www.dailymail.co.uk/health/article-1246075/TV-boss-bed-thought-overdone-Infact-crippling-disease-blind-you.html>



Many people from around the southern region had contacted us either by email or telephone seeking advice and enquiring about support groups in their area. So an open invitation was sent out to meet us the following day in our hotel. We were very pleased by the number of people who arrives, some from long distances throughout the South East.

Over coffee, lunch and the odd glass of wine support and advice was given, experiences shared and friendships formed.

## 'You are not alone'... Launch of NE DVD

PMR-GCA UK North East support was first set up in May 2008. On 12 May last year, we had a formal launch and our DVD 'You Are Not Alone' at the Centre for Life in Newcastle upon Tyne.

There over 200 hundred people who came to the opening in the morning, from all over the region and wider a field, including representatives from PMR-GCA UK and PMR-GCA Scotland. We also had a very lively question and answer session where patients could ask questions of the medical people present. BBC TV Look North and BBC Radio Newcastle publicised the event on the day as well as National and Local newspapers. In the afternoon we sponsored a meeting of Rheumatologists, Ophthalmologists who work in the North East to listen to lectures from Professor Dasgupta, and consultant rheumatologists and ophthalmologists on PMR-GCA.

We have received some very positive comments about our DVD. "For all the newly diagnosed people seeking help this DVD answers all the

*questions and best of all will take away that feeling of being alone .....it left me with a warm glow that people out there are now actually listening and caring and acting to try and find a cause and a cure for these potentially devastating conditions."*



*Above: The Medics who gave us their time and the DVD possible, with Mavis, Alan, Margaret and Pam.*

## Those little red pills . . . . .

If it is some time since you were first diagnosed with PMR or GCA, the chances are that you have got used to taking coloured prednisolone pills – red for 5mg, and brown for 2.5mg, for instance. This coloured coating is an ‘enteric coating’ (EC) that we were told is to prevent irritation of the stomach lining. Some members are reporting that their doctors are switching them over to plain white non-coated tablets, and are asking why this is happening, and whether they should be concerned.

Our medical advisors tell us that the EC tablets are hugely more expensive than the white ones (over 17 times as much!) on NHS contract prices, but this isn't the only reason. It has also been established that the health benefits of taking the EC tablets are questionable. A recent review of the evidence by UKMI (the UK Medicines Information service) suggests there is no evidence that EC prednisolone causes less peptic ulceration than plain tablets. And the EC tablets can even cause problems by interfering with absorption.

So it looks as though patients have few grounds for bemoaning the passing of the little red pills unless..... we can't tell what dosage we are taking! Patients taking a combination of tablets might get confused if all the prednisolone is white, regardless of the strength. It puts more onus on the patient to keep track and get the dosage right.

## CLASSIFICATION CRITERIA FOR PMR

We've heard it said that PMR is a tricky illness to diagnose because it ‘mimics’ other illnesses, such as rheumatoid arthritis, fibromyalgia and various causes of shoulder pain. Now progress is being made towards adopting an international set of classification criteria, following five years' work that started with a consensus work group meeting at the Third International Conference on GCA and PMR held in Cambridge UK in 2005, kicking off an international consensus study.

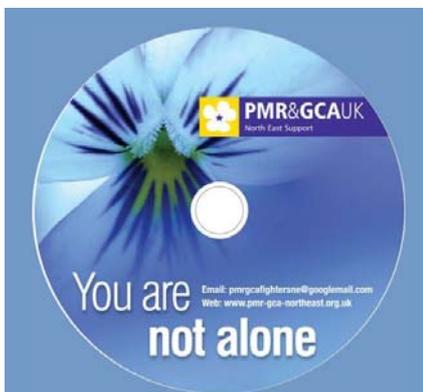
The PMR classification criteria were presented at the American College of Rheumatology 2010 at Atlanta and were immediately hailed as one of the leading highlights of the meeting.

New PMR should be suspected in people greater than 50 years of age presenting with new onset (less than 12 weeks) bilateral shoulder pain and raised inflammatory markers. Mimicking conditions should be considered and excluded including the conditions studied as comparators in the study.

The recommended approach and necessary investigations should follow the BSR guidelines on PMR. In this group of cases their further clinical features can be rated on the basis of a scoring algorithm to identify cases of PMR suitable for low dose steroids. These consist of four clinical and laboratory criteria along with optional ultrasound (US).

Ultrasound is optional to the main criteria since it is not yet widely available across the world. Evidence suggests that ultrasound significantly improves specificity of PMR diagnosis and hence is a recommended investigation for PMR.

These criteria are presently designed for recruiting cases to clinical trials and research studies. They are not yet validated as diagnostic criteria although new research studies are being developed to test the criteria in clinical practice. If you are interested in finding out more, please email us on [pmrgca@googlemail.com](mailto:pmrgca@googlemail.com)



*I've watched my copy of "You are not alone" and feel so grateful to all those people who have given their valuable time to help highlight the existence of PMR and GCA, including rheumatologists, a pharmacist, a physiotherapist, a dietician, an MP and, not least, that little band of tireless fighters in the North East Support Group.*

## Focus on..... East Anglia



Early in 2004 a small group met to discuss the setting up of the originally named Polymyalgia Rheumatica Support. After three years of PMR Jennifer Nott was feeling well enough, with help, to set up the telephone help and support service which she herself had sought in the early days of her illness, but not found.

The main thrust of our service today continues to be the helpline, which can provide counselling support, and is a lifeline for sufferers. The service is available for anyone in the UK, with information and newsletters distributed to contacts, and twice yearly meetings held locally in Suffolk. These are very much appreciated by our members who may have either PMR or GCA, or both.

As other groups subsequently started up in different regions of the country, we added the 'East Anglia' moniker to our title. In 2009, when PMRGCAuk was formed, in line with national policy we adopted our present title, officially embracing those people with Giant Cell Arteritis. We marked this change by circulating all our 500 contacts with a questionnaire to record those with GCA. The returns show that approximately 10% of our members have GCA. We invited Consultant Rheumatologist Dr. Richard Watts of Ipswich Hospital to speak at our meeting in October 09 about the relationship between the two illnesses.

Our twice yearly meetings attract people from a very wide area – as people continue to seek our help from all over the UK. In October 2010 we attracted over 90 people who came to meet and compare notes with others 'in the same boat', and to hear our speaker, Specialist

Rheumatology Nurse Ruth Slack from West Suffolk Hospital. A surprise visitor was Ruth's colleague, Consultant Rheumatologist Dr David O'Reilly. The speakers were delighted with the size of the audience, whilst the audience was delighted to hear the professionals!

Of course our progress would not have happened without the backing of our committee. Originally we had a 'steering group' of four, with John Parsell and Jennifer Nott running the help line. We now have an established organisation with a committee of eight, with Jennifer as Chair/Organiser. John is in charge of publicity, contacting news outlets to keep our profile high. Treasurer Paul Gill looks after our membership and financial affairs. Small grants from local sources such as The Suffolk Foundation help with running costs.



### *Dr. O'Reilly & Ruth Slack with Members of our Committee chat with Jennifer*

We have a brilliant team of envelope-stuffers who make sure our twice yearly newsletters are distributed. This Autumn we have sent 350 newsletters by post and another 100 by email. The committee members are invaluable in setting up our meetings, held in the local Community Centre, where they also provide refreshments.

Our service continues to thrive and provide for the many people who find comfort and support as they experience the difficulties caused by PMR and GCA.

Jennifer Nott. Chair/Organiser

## Meanwhile, in the South West....

Support in the South West started in 2008 with a support group meeting in Taunton with email and phone support for the rest of the area. However Wednesday 28<sup>th</sup> July was a "Red Letter Day" as the first meeting of the Bristol Support Group was held. Sue Halliday is now our contact in Bristol. Sue has PMR herself and so has her cousin Grace. The meeting was held at her cousin's home, which proved to be a very comfortable venue.

We were very fortunate that Professor John Kirwan, BSc, MD, FRCP, head of the Rheumatology Unit at the Bristol Royal Infirmary, and an expert on PMR-GCA, was able to attend. He gave a very informative talk about his research, with particular reference to work concerning IL6, followed by a lively question and answer session. No support meeting would be complete without a "cuppa" and this was accompanied by some of Sue's goats' butter wheat free Mini Muffins.



From left to right: Sue Halliday, Linda Hill, Diane Francis, Dick Hollis, Prof. John Kirwan BSc,MD,FRCP, Gwenda Townsend, Wendy Morrison & Grace Cooper

The last meeting held at the BRI on 2nd November was so well attended there was standing room only. Many of the attendees were patients of the clinic. We had a busy afternoon with talks by John and Samy Zakout, his researcher, a tour of the facilities and an invaluable question and answer sessions. We can't thank John and his team enough for the boost this has given us.

The South West groups are going from strength to strength.

To contact us:-

Ring the National Contact No. on page 7 and ask for Wendy Morrison or Sue Halliday.



## Polymyalgia Rheumatica and Giant Cell Arteritis Scotland

PMR-GCA Scotland, the first charity in the UK specifically for PMR and GCA, was known formerly as Tayside PMR & GCA Support. This year we have acquired an office as the volume of enquiries has escalated and we need more volunteer help. The office was furnished with a very generous grant from Awards for All. We have several excellent volunteers who, sadly, are all job-seeking graduates.

In 2009 we sent out 250 information packs and by September this year we have sent out 230. We are receiving too many calls from people who are distressed and feeling isolated and have had several from people who have lost vision, which is unacceptable.

We have made contact with the Minister for Health and Sport in the Scottish Government, Shona Robison, who was shocked at what she was told and has been very supportive and helpful. She put us in touch with the civil servant who is Head of the Long Term Conditions Unit in the Scottish Government Health Directorate, who has been extremely helpful and supportive. He is to speak to colleagues in the Health Directorates involved in primary care and dentistry about how we might try to raise awareness of PMR and GCA amongst GPs and dentists in Scotland. He is also to make colleagues who are responsible for the recently-introduced Abdominal Aortic Aneurysm screening programme aware of the link to PMR and GCA.

Our monthly meetings are now well established and attended by people from as far away as Edinburgh and even Peebles.

## Profile... Bhaskar Dasgupta

Our Honorary President, Professor Bhaskar Dasgupta MBBS, MD, FRCP (Consultant Rheumatologist & Clinical Director for Research), was a prime mover in the efforts to get the national PMRGCAuk charity off the ground.

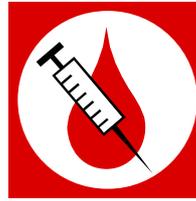


*Prof Bhaskar Dasgupta speaking at the NE region launch, May 2010*

Professor Dasgupta leads the Southend Rheumatology Dept. which offers specialist services for complex inflammatory arthritides. The Unit is renowned for research, teaching and training. He has developed academic collaboration with the Essex University. Under his leadership the hospital has developed a research culture responsible for the second highest portfolio activity within the Essex & Hertfordshire CLRN.

This summer, he and his wife attended a Royal Garden Party at Buckingham Palace, at which they were presented to the Princess Royal, who was very interested to hear about the work to prevent sight loss caused by GCA.

In the little spare time that he has, Bhaskar, who lives with his family in Southend, plays Indian classical music, a passion and a talent he inherited from his parents.



## Jargon Buster

### What are the ESR & CRP?

There are two types of tests to measure inflammation levels – ESR and CRP, which are known as inflammatory markers. Generally speaking, the higher the readings shown by your blood tests, the more inflammation there is. However, tests don't always indicate your symptoms.

**ESR (erythrocyte sedimentation rate).**

This is a simple test to indicate the level of inflammation in your body. It is a general test and does not by itself mean you have PMR or GCA. There are many different causes of inflammation. Normal results are usually below 10 but ESR increases naturally with age. It is normally higher for women than for men.

**CRP (C-reactive protein)**

This is a more sensitive test to measure the level of inflammation in your body. Normal levels are usually below five, and it is a general test that will detect levels of inflammation or infection from causes other than arthritis. CRP picks up things like a chest infection, but is very sensitive to recent changes in inflammation. "A result over five is raised and we would want to know why" " says rheumatologist Dr. Chris Deighton, who contributes to *Arthritis News*.

Professor Dasgupta Consultant Rheumatologist of Southend Hospital says specifically for people with PMR and GCA;

*"In particular both ESR and CRP can go up due to many reasons apart from PMR and GCA and sometimes [the results] can be normally borderline raised without a very good reason in a healthy person"*

Professor Dasgupta further stresses the point in his comment that "Conversely both active PMR or GCA can occur with normal or near-normal blood tests and the diagnosis and steroid adjustment for these conditions should be primarily based on clinical assessment".

## Contact us!

**PMRGCAuk has a new phone number!**

**0300 111 5090**

We chose this number deliberately, because people from 50 to 90 get PMR and GCA!

From anywhere in the UK you can call **PMRGCAuk** for the cost of a normal landline call. If you have a phone package with 'free' bundled minutes, calls to 0300 numbers are included in the free minutes, so it may cost you nothing at all, even from a mobile phone.

This number will be available both in the evenings (until 8pm) and at weekends. If you do go through to the answering machine, rest assured that if you leave your name and number we will come back to you within 24 hours (48 hours at the weekend). Please be assured that although we are volunteers we take our contact with you very seriously and will respond as soon as we can.

You can also write to us on email – [pmrgca@googlemail.com](mailto:pmrgca@googlemail.com). Either way we assure you a sympathetic ear, some good information, and contact with your nearest support group or support volunteer.

## Follow us on Facebook!

<http://www.facebook.com/pages/Polymyalgia-Rheumatica-and-Giant-Cell-Arteritis-UK/148618845177929>

## Become a member . . . . .

(you'll find a membership form on the back page)

The Trustees and Management Team of PMRGCAuk very much want you to feel part of the wider national UK picture. We are therefore inviting you to become subscribing members of this national organisation, which reaches all parts of the UK. This would enable you to receive information:

- About medical advances in the diagnosis, and treatment of the two illnesses.
- On managing Polymyalgia and Giant Cell Arteritis in practical day to day living.
- To make contact with others experiencing the illnesses either through a Regional Group or with individuals.

PMRGCAuk strives to promote awareness amongst the public, to raise the profile of the two illnesses in the health and medical professions, and in employment.

- Campaigns for fast and effective diagnosis and treatment to prevent sight loss resulting from undiagnosed GCA.
- Serves as a co-ordinating body for the established Regional Groups.
- Encourages the setting up of new groups.
- Works closely with other supportive organisations such as Arthritis Care and Arthritis Research UK
- Promotes encourages and participates in research into PMR and GCA.

PMRGCAuk has an active role in ensuring that you are not alone in enduring the trials and tribulations brought about by the symptoms and medication of the illnesses.

PMRGCAuk now needs ongoing financial support to secure its established purpose. Your membership by annual subscription will play a vital part in order that the benefits above are there for you and for the many people who experience the sudden and often devastating effects of both PMR and GCA.

Please join us today!

Kate Gilbert PhD, Chair, PMRGCAuk

## We'd like to thank.....

PMRGCAuk runs almost entirely on voluntary help and we would like to thank the following people for contributing to this newsletter:

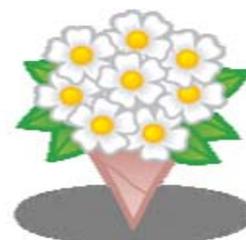
Jennifer Nott

Wendy Morrison

Mavis Smith

Pam Hildreth

Jean Miller



## Membership Application Form

Thank you for taking up membership of PMRGCAuk. Your support will help make a real difference to the lives of people with these conditions, and contribute to our campaign to prevent the threat of visual loss.

Please print clearly.

Forename(s):			
Surname:			
Occupation (if employed):			
Address:			
Postcode:		Tel:	
Email Address :			
Date of Birth (optional):			

### Membership Subscription Rates (please tick relevant boxes)

- Individual: £20.00 per year
- Concessionary Individual: £10.00 per year (retired or unwaged):
- I would like to add a donation of £.....

### Gift Aid

If you pay Income Tax, Gift Aid will increase the value of your payment by allowing us to reclaim basic rate tax on your Gift.

- YES – I would like my subscription/donation to be treated under the Gift Aid scheme.
- NO – I am not able to Gift Aid my subscription.

You can cancel this declaration at any time by notifying PMRGCAuk

### How would you prefer to receive information? (please tick relevant box):

- By post  By email

Signature.....Date.....

Please return this form with your cheque/postal order (made payable to PMRGCAuk) to:  
Mr A Walkington, Treasurer, PMRGCAuk, 5 Deramore Drive, Badger Hill, York YO10 5HW