

You are not alone

Polymyalgia Rheumatica and Giant Cell Arteritis

Newsletter Autumn/Winter 2011

Letter from America



Hi, my name is Rick. I live in South Florida, USA and have been dealing with PMR now for 16 months.

I found the PMR&GCA UK North East Support site with a Google search when looking for 'PMR support forum'. This led me to the patient experience discussion forum

– where someone had posted a link for the main site. This site has been an excellent resource for me. I need to thank all those individuals responsible for making that all-important information on PMR and GCA available on the internet. Thank you.

I was diagnosed with PMR in March 2010. For three or four weeks before that I had been dealing with severe muscle pain in my shoulders, arms, hips, quads and buttocks. The pain was so bad in the morning that I had trouble getting out of bed. Then I couldn't shower or wash my hair until later in the afternoon when I had loosened up some. Even then I could only get one arm above my head – using that arm to help lift the other arm. Dressing was difficult and I had to give up wearing T-shirts (*don't know how the ladies put on those things that have to be fastened in the back?*).

In January 2010 I injured my right shoulder when lifting my mom from the seat of my car into a wheelchair. X-ray and MRI showed extreme tendonitis and bursitis in three areas of my right shoulder – but no tear. I was getting physical therapy for my shoulder for a couple months. All of a sudden things started to get worse where it seemed like the tendonitis had spread to my left shoulder. This made no sense! Then I noticed pain in my hip joints when getting

in and out of the car. One morning, after struggling to get out of bed, I couldn't even reach the faucet to turn on the water to brush my teeth. I thought I was going crazy!

My physical therapist suggested I see a rheumatologist because she knew something else had to be going on. I called a rheumatologist and made an appointment. After a physical exam and pelvic X-ray (which showed normal), he said he needed to run some blood tests, but was pretty sure I had PMR. He said I had the classic symptoms (bi-lateral hip and shoulder pain). He suggested I start on prednisone – a medium dose of 20 mg per day... 10mg after breakfast and 10mg after dinner. He said if I started to feel better it would help confirm his diagnosis. In just 24 hours I felt about 30% better. After two days I was 50% better. After one week of 20 mg daily I was 80% better!

At my rheumy's follow-up a week later, he said he was 98% confident in the PMR diagnosis. My blood work showed ESR (Sed rate) was 85 and CRP high at 6.4 – indicating inflammation. He also said the CBC (complete blood count) test showed I was borderline anaemic. My TSH (thyroid function) and RA (rheumatoid factor) both showed normal. My rheumy wanted me to stay on 20mg/day for another three weeks after which he would run the blood tests again – and hopefully be able to start lowering my prednisone dosage. The next blood test showed much improvement – ESR was 9 and CRP was normal. I asked my Rheumy how long PMR usually lasts. He said between six months and six years. Well, it's been longer than six months for me as I'm now at 16 months and on 9 mg/day.

I wish all my fellow PMR sufferers the best. Remember, that prednisone (or prednisolone) doesn't cure PMR, but gives us our life back... **almost.**

Need help?

Want to join?

Please get in touch:

PMR&GCA UK North East

Tel: 0191 411 1138

Email: pmrgcafightersne@googlemail.com

www.pmr-gca-northeast.org.uk

Now for some good news...

My good news, and you can share this with others who are still searching for that glimmer of hope, is that 31 July saw me take the very last prednisolone steroid.

I have been pain free and symptom free for a couple of months now. I see my consultant at the end of September and I expect that he will discharge me. My journey with PMR has taken me three and a half years since I was diagnosed to complete and it has taken me to some dark places that I do not want to revisit.

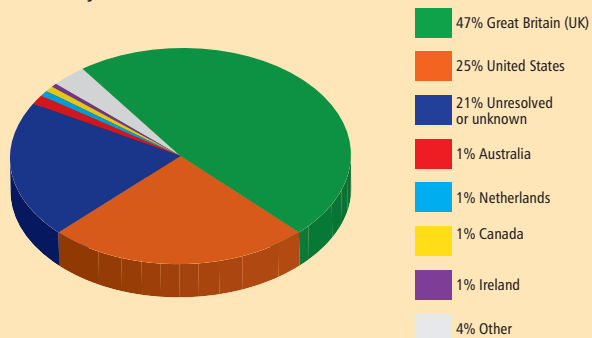
But now I am on top of the world, I am losing weight with the help of Slimming World who have supported me all through this terrible time when we saw my weight steadily rise week after week, although I was eating sensibly and sticking to the programme.

I send my kind regards and hope that many more of your members will have the happy end to their story that I am having now.

Beryl

A record 42,000 visitors per month!

Our website www.pmr-gca-northeast.org.uk is still attracting many people. Our busiest month saw over 42,000 visitors which averages out at 37,000/month over the year.



An educated point of view...

After an initial 'blip' by my rheumy of all people (*rolling eyes*), and my doc trying to sort it out, I am now more or less being 'allowed' by my rheumy to take it at my own pace! I am going down only by 1g a month at the moment and have reduced from 20mg to my current 14mg. Things will be different once I reach 10mg because of the no reduction more than 10% of the current... have already mentioned this to my doc to prepare her!

Fantastic info on the PMR&GCA UK North East site and for that I thank them (*very happy*). If I had not been directed to this forum by my doc and met the wonderful people here who have been brill at 'educating' me in my PMR and steroids I would have been lost...

I now feel that when I speak to my rheumy (I am seeing him more than my doc at the moment), I speak from an 'educated' point of view and have the facts to hand... well allowing for 'steroid' brain that is (*laughing laughing*).

So wishing you well...

Name withheld on request

DVD, feedback...

Yes, I did find the DVD very informative and clear.

To be honest, I did know the script, but only because as soon as I clocked what GCA was, I was able to do my own internet research, looking up medical research articles (*not a lot*) because that is my interest and my job.

So by the time I got the DVD it was like feedback.

However, that is not a criticism... I very much liked the question/answer aspect. A block presentation would not have had the same impact, and the questions were what I would have needed had I not known anything.

I would have liked more patient feedback, maybe like the stories on the website, and what it is like to actually live with the condition. Also, more about real life and coping with employment, family, benefits, integrating home life with illness/disability. That is still my problem, will I ever get my old life back but, realistically, who knows?

Really appreciate all the work you lot have done with the support groups, forum etc.

Name withheld on request

You are not alone, DVD, still available...

The DVD was made, not only for patients, but for relatives, friends, carers and those in the medical profession who want to widen their knowledge of the impact on patients. To order your **free copy**, please see contact details on front page:



£5

Covers the cost of post and packing

Your immune system

Your immune system is the police force in the body that monitors the borders and registers that something foreign has arrived.

It might be a cold virus, the flu virus, a bacterial infection, an insect bite or sting or pollen or other thing that causes an allergic reaction. Then it mobilises the front line forces and the white blood cells rush to the place the foreign visitor has been found and surround it to neutralise it. If there is a lot of the invader, the reaction is bigger and you get a bit of a temperature maybe or a big red reaction around the bite or an asthma attack if you are sensitive. If the invader is one your body hasn't met before, it takes a bit longer for the forces to develop a way of tackling it. If it has already been seen before, the repelling action is quicker and more effective.

The flu jab (or any vaccination) tricks the body into thinking it has dealt with it before – an inactive form of the virus or bacterium is injected into the body so it can learn what the outside of the bug looks like and manufacture the armament to deal with it best. Some jabs have live virus in them but it all depends on what disease it is to protect you from.

When we take steroids it is said our immune response is impaired and we are at more risk of getting infections and not being able to fight them off. I don't know whether that is right or not – my experience has been I have had far fewer colds since I started taking pred! It is recommended that long-term steroid takers should get the flu jab (and maybe the pneumonia one as well) but since I spend most of my time out of the UK, it's never been offered to me.

Autoimmune means that something has happened in your body that has upset your immune system and it now thinks your own body is the enemy. This means that some of the white blood cells responsible for defence turn on the body tissues and try to destroy them: it might be muscles or nerves or the cartilage lining of the joints. The result is diseases like rheumatoid arthritis or muscular dystrophy – even diabetes or thyroid problems can sometimes be due to an autoimmune problem. If they can identify which cells are involved – it isn't all of them, it may just be one sort and there are lots – it is sometimes possible to make a drug that just works on those cells and stops them. Usually though, you have to damp the whole lot down with the most effective drug.

It is thought that PMR is the result of some sort of autoimmune effect in the body but they don't know what causes it or any of the minute details. The only drug that works at present is one of the group of drugs called corticosteroids – prednisolone or a close relative. This works on the inflammation that is the cause of the symptoms and allows us to function with less stiffness and pain. It doesn't cure it, it manages it – just like giving a diabetic insulin doesn't cure the diabetes. So you need to keep taking the pred as long as the disease is active.

Sometimes this underlying autoimmune activity dies away and stops encouraging the inflammation and if that happens you wouldn't need the pred any more – which is why you are told to keep trying to reduce the dose you are on to see if it has gone away. But if when you reduce the symptoms come back in a week or so and continue to get worse, you need to go back to the last dose you were comfortable at because that is the amount you need to control the disease.

When you take a high enough dose to just deal with the inflammation you are getting the benefits with as few of the side-effects as possible, the lower the dose the fewer the side-effects. There is no point trying to 'manage' at too low a dose – it isn't achieving anything except you are taking steroids that aren't helping but not being very good for your body in the long term. You start at a dose that is high enough to definitely deal with the inflammation and relatively quickly, usually you get an improvement of well over 50% within 24 to 48 hours and this is absolutely typical in PMR. If you don't get that sort of response your doctor may question whether it really is PMR – for example, late onset rheumatoid arthritis can look very similar and is often confused with it.

“You start to reduce the daily dose bit by bit until you find the lowest dose you are happy with.”

Then you need to stay at that dose for a while, maybe months, maybe a year or two at least – it all depends. You will try a reduction every so often to see if it has gone away or you can manage with a lower dose. Some people go into remission in a couple of years – and that is the figure many doctors say to patients – but most people will take more than that. About half need between two and four years, about a quarter never really get off steroids altogether but stay on a very low dose for years, sometimes for life.

Hope this helps you understand it all a bit better.

Eileen Harrison Physiology
BSc(Hons) St Andrews
Translator of Medical and Science Documents

Middlesbrough Area 1 News

April

The Secretary, Pam Hildreth, was delighted to welcome old and new members and visitors from Manchester who were hoping to form a Support Group in the North West area.

As this was the AGM, there was no Guest Speaker present.



Members listening intently

The Treasurer, Alan Tailford, gave a short report on finance, and advised that although it looked like a healthy balance, outgoing commitments for the following year would reduce that balance substantially.

Margaret Wright, Vice Chair, presented the Annual Report and gave a brief outline about future projects.

Discussion took place with regard to membership fees and method of payment.

Mavis Smith reported on the National Organisation PMRGCAuk and reminded members that copies of the National Newsletter were available on the leaflet table. She asked members to take three copies, read one and then distribute the copies in doctors' surgeries, hospital rheumatology and outpatients departments.

Pam Hildreth, Secretary, advised that Tees Valley Community Foundation had awarded a grant of £480 to be used in the Tees Valley area only.

The new Internet Forum is gaining members rapidly – website address is www.pmrangca.forumup.co.uk.

Middlesbrough next meeting

Wednesday 11 January 2012 at 1.30pm Marton Country Club preceded by post-Christmas dinner



Annie Willerton (right) with group members

June

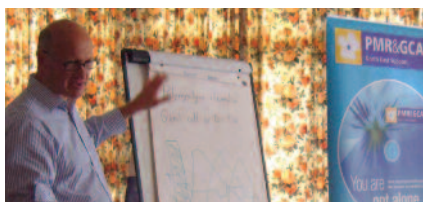
Guest speaker at this meeting was holistic massage therapist Annie Willerton. Annie has both PMR and GCA but is almost recovered. She gave an account of her journey through the illness and advice on alternative therapies, supplements etc which helped her. She explained how a good massage therapist should be trained and what to expect.

Sister Elaine Doyle, Rheumatology Nurse, James Cook University Hospital attended the meeting as she wished to meet members and see how the Support operated.

Pam reported that she had been unable to attend a National PMRGCAuk meeting held in London. Subsequently, Pam had been advised that Dr John Kirwan, BSc, MD, FRCP, Consultant Rheumatologist and Professor of Rheumatic Disease University of Bristol, is conducting research into a new type of prednisolone. The members wished Dr Kirwan well in his research.

September

Guest speaker was rheumatologist, Dr M Plant, who gave a presentation on the diagnostic procedures, management and treatment of PMR



Dr Mike Plant

and GCA. He also discussed alternative steroid sparing drugs. A lively question-and-answer session also took place. Please email, write or telephone for a copy of the presentation.

Gateshead Area 2 News

April

Our guest speaker, Mark Thomas, Pharmacologist, works at the Pharmacy Department at the Queen Elizabeth Hospital, Gateshead. Mark gave a very interesting and informative talk, and a brief introduction to the Pharmacy Department, ranging from the role of a Pharmacist, and services offered. There was also a lively debate and question-and-answer session at the end of the talk.



Mark Thomas

Mark outlined some of the ideas for a Steroid Card Project. Members present completed evaluation forms for this project.



Members with Cllr Michael Wood, Mayor of Gateshead 2010-2011

Cllr Michael Hood, Mayor of Gateshead, also attended for part of the meeting, gold necklace and all! The group was originally helped with funding from Gateshead Council for their set up costs three years ago, and their offices were used for our DVD, 'You are not alone'. The Mayor answered questions on his role as Mayor of Gateshead and also donated £100 from the Mayor's Charity Fund.

June

Dr V Saravanan, Consultant Rheumatologist, spoke on the ongoing research into both cause and cure of PMR and GCA. He also referred to current research projects looking for friendlier medication. Applications for funding



Dr V Saravanan MD, guest speaker

for research were being sought and some grants had been made. Progress was slow, but the scenario was changing as both PMR and GCA's profile was being raised.

Dr Saravanan explained how prednisolone and methotrexate worked and how it controlled the symptoms.

The dosage and the withdrawal of this medication is dependent on the individual, so this could only be discussed in general terms.

A question-and-answer session was held on prednisolone, methotrexate, alternate day therapy, and other diverse questions were answered.

The members present thanked Dr Saravanan for his help and advice.

September

At our group meeting on 26 September 2011, we were delighted to welcome Janet Hume (Fundraiser) from the Great North Air Ambulance. She showed a video of the doctors (who all work on a non-paid, voluntary, rota basis), paramedics and pilots in action at rescues, as well as people who are eternally grateful for the service which saved their lives. She explained that the Air Ambulance runs on donations only and receives no government support. On behalf of the members and trustees of

PMR&GCA UK North East Support, Margaret presented Janet with a cheque for £50 from funds raised in the past from group raffles.

We were also delighted to welcome Ragnar Domstad from Sweden (see page 6).



Margaret Wright presenting the donation to Janet Hume, Great North Air Ambulance

Gateshead next meetings

30 January, 26 March, 25 June & 24 September 1.30pm
 Wailes Room, Gateshead Library,
 Prince Consort Road. Gateshead.

NB: All except the January meeting will have Guest Speakers.

Two new groups have been formed and we were glad to respond to their request for assistance based on our own experiences.

Surrey



Surrey Group

The first meeting took place on 19 July at the Kingfisher Inn and was well attended by people from a wide area of Surrey and from Sussex.

It was a very friendly, informal meeting over a drink and a bite to eat after which a group photograph was taken (*below*), and it was obvious everyone welcomed the opportunity to share their experiences with others who understood exactly what life was like with PMR and/or GCA.

West Sussex and Brighton

Catie Pickersgill promoting PMR GCA UK
 I did my best to advertise wearing our T-shirt.



Christine Young and Catie Pickersgill (*pictured*) are working together to set up a group in West Sussex and Brighton. Their first meeting was on Tuesday 20 September.

There were six of us present and of those two were husbands and one a daughter! It gave us the opportunity to meet with Jean Dubock who has, unfortunately, lost most of her sight due to GCA which was not caught and treated in time.

We hope to expand in the future and to this end a member offered to display leaflets at the hospital where she is employed. We look forward to our next meeting.



PMR&GCA UK Northeast 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



Acupuncture

I will always remember sitting in lecture theatres as a student nurse and passing round samples of Chinese herbs during a lecture on alternative medicine.

Little did I know how this was to be my medicine in years to come... but I was fascinated. Years later I was nursing a physiotherapist who had had cardiac surgery, on an intensive care unit in London. All had gone well and he was going back to the ward. We chatted a little and he said that he had also qualified as an acupuncturist and, unlike many of his colleagues who had done a few days 'dry needling' training, he used his full skills in a far more holistic and powerful way. Had I not quizzed him a bit more I may still be doing night shift! What he had to say absolutely blew me away. I had never heard of anything so fascinating. Like a dog with a bone that I had only heard of and never tasted, off I went in search of this 'magic'. I applied to the same college that my patient had studied at, who only accepted medical people onto the course. This training was going to be very expensive and I actually gave up on the idea of it... but not for long. I couldn't let it go and before I knew it I was a student acupuncturist.

The training was very demanding and meant I had to drop to part-time hours to fit in all the study days, clinic days and homework. Oh my word, I had never studied so hard and I was loving it! I had returned to midwifery (one of my other hats) and looked forward to also treating women in pregnancy with this amazing Oriental art.

More than three years later I was qualified and eager to start my own business. It took another four years before I could give up my nursing career and concentrate on my business full time. At last I could help people in a more natural way with a safe and effective medicine that they had sought for themselves. Of course, despite promising myself that I would never have to study like that again, Chinese medicine makes you hungry. A practitioner of TCM (Traditional Chinese Medicine) is always after more knowledge and is an eternal student. I soon realised that studying Chinese Herbal medicine was the only way to satiate that hunger. 'Here we go again', I thought.

Eleven years on from qualifying as an acupuncturist, I am now also a Chinese herbalist. This has also made me a better acupuncturist because my deeper understanding of TCM helps me diagnose patterns of disharmony and devise treatment plans more effectively than ever before. I have a special interest in pain of any type, whether emotional or physical, and in fertility issues and pregnancy. I believe in integrated medicine, and having experience on both sides makes me a more confident practitioner able to offer advice holistically.

I work from four clinics around Newcastle, Gosforth, Jesmond and the Coast and can be contacted via e-mail at info@nicolascholesacupuncture.co.uk or by phone on **07949 107 167**.

Please feel free to contact me for advice or have a look at my website www.nicolascholesacupuncture.co.uk

Nicola Scholes MScCHM LicAc MBACc MRCHM

Reducing your steroids

Ragnar Domstad from Sweden joined us at our meeting held on 26 September. After a talk by the Great North Air Ambulance, Ragnar gave a presentation on 'Reducing your Steroids'.

Before our Support Group came into being, when we were 'pmrfighters' and were looking for other people with PMR and GCA, Pam, our secretary, and Mavis, our chair, met a fellow PMR patient, Ragnar Domstad over the internet via Patients Experience Forum. Ragnar, who lives in Sweden, has kept in touch with us over the past four years and we have his story on our website.

Ragnar devised a reduction method that enabled him to reduce his prednisolone very slowly.

'Ragnar's Method', as it became known over the internet, helped people with PMR in Australia, USA, New Zealand and in Europe. Hence many of our contacts have tried it and it has worked for quite a few of them. Ragnar travels all over Europe giving talks on many subjects but his most interesting one is his story and the 'Ragnar Method' of reducing steroids.

Ragnar offered to come to Newcastle and talk to our members about his reduction method, his success story and how he is now free from PMR. Ragnar was most impressed with the Angel of the North and our public transport system. More details can be found on our website.

Ragnar Domstad



Vitamin D deficiency

Vitamin D is important for good health, growth and strong bones. A lack of vitamin D is very common.

Vitamin D is mostly made in the skin by exposure to sunlight. Most foods contain very little vitamin D naturally, though some are fortified (enriched) with added vitamin D. A mild lack of vitamin D may not cause symptoms but can cause general aches and pains. A more severe lack can cause serious problems such as osteomalacia in adults, described below. Treatment is with vitamin D supplements. Some people are more at risk of vitamin D deficiency, and so are recommended to take vitamin D supplements routinely. These include all pregnant women, breast-fed babies, children under 5, and people aged 65 and over. Also, people who do not get much exposure to the sun, people with black or Asian skin types, and people with certain gut, liver or kidney diseases.

What is vitamin D?

Vitamins are a group of chemicals that are needed by the body for good health. Vitamin D is a fat-soluble vitamin. The fact that it dissolves in fat is important, because it means the body can store it for use. Unlike other vitamins, we do not need to get vitamin D from the food that we eat. This is a good thing because most foods contain very little vitamin D naturally. Foods that contain vitamin D include:

- Oily fish (such as sardines, pilchards, herring, trout, tuna, salmon and mackerel).
- Egg yolk.
- Fortified foods (this means they have vitamin D added to them) such as margarine, some cereals, infant formula milk.

Situations where the body is unable to make enough vitamin D

- People who get very little sunlight on their skin are also at risk of vitamin D deficiency. This is more of a problem in the most northern parts of the world where there is less sun. In particular, people who stay inside a lot. For example, those in hospital for a long time, or housebound people.
- People who cover up a lot of their body when outside. For example, wearing veils such as the niqab or burqa.
- People with pigmented (coloured) skins. This includes black and Asian people. Caucasian (white) people are less at risk.
- Strict sunscreen use can potentially lead to vitamin D deficiency, particularly if high sun protection factor (SPF) creams (factor 15 or above) are used. Nevertheless, children especially should always be protected from the harmful effect of the sun's rays and should never be allowed to burn or be exposed to the strongest midday sun.
- Elderly people have thinner skin than younger people and so are unable to produce as much vitamin D. This leaves older people more at risk of vitamin D deficiency.

- Some medical conditions can affect the way the body handles vitamin D. People with Crohn's disease, coeliac disease, and some types of liver and kidney disease, are all at risk of vitamin D deficiency.

- Vitamin D deficiency can also occur in people taking certain medicines – examples include: carbamazepine, phenytoin, primidone, barbiturates and some anti-HIV medicines.

Not enough dietary vitamin D

Vitamin D deficiency is more likely to occur in people who follow a strict vegetarian or vegan diet, or a non-fish-eating diet.

How common is vitamin D deficiency?

It is very common. A recent survey in the UK showed that more than half of the adult population in the UK has insufficient levels of vitamin D. In the winter and spring about 1 in 6 people has a severe deficiency. It is estimated that about 9 in 10 adults of South Asian origin may be vitamin D-deficient. Most affected people either don't have any symptoms, or have vague aches and pains, and are unaware of the problem.

Symptoms in adults

- General vague aches and pains are the common symptoms.
- In more severe deficiency, there may be more severe pain and also weakness. This may lead to difficulty standing up or climbing stairs, or can lead to the person walking with a 'waddling' pattern. This is known as osteomalacia.
- Bone pains may develop and are typically felt in the ribs, hips, pelvis, thighs and feet.

How is vitamin D deficiency diagnosed?

It may be suspected from your medical history, symptoms, or lifestyle. A simple blood test for vitamin D level can make the diagnosis. Blood tests for calcium and phosphate levels and liver function may also show changes linked to a low level of vitamin D. Sometimes, a wrist X-ray is done for a child. This can assess how severe the problem is by looking for changes in the wrist bones.

What is the treatment for vitamin D deficiency?

The treatment is to take vitamin D supplements. This is a form of vitamin D called ergocalciferol or calciferol. Vitamin D can be given as an injection or as a medicine (liquid or tablets). Your doctor will discuss the dose, and best treatment schedule, depending on your situation, age, severity of the deficiency, etc.

Prognosis (outlook) in vitamin D deficiency?

The outlook for vitamin D deficiency is usually excellent. Both the vitamin levels and the symptoms generally respond well to treatment. However, it can take time (months) for bones to recover and symptoms such as pain to get better or improve.

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International

EULAR & ACR

The European League Against Rheumatism (EULAR) and The American College of Rheumatology (ACR) asked the International PMR Study Group to develop recommendations on PMR. Mrs Pam Hildreth, Secretary PMR&GCA UK North East Support, has been invited to participate as a Patients Representative. We have learned that Mrs Jean Miller PMR GCA Scotland has also been invited to participate.

Marijke Foundation Netherlands

Han, Secretary and Founder of the Marijke Foundation, has advised us that the National Medical Research Foundation (NMRF) Arizona USA, has made contact with them and they are working together on cause and cure. Many of our members have taken the time to fill in the 'symptomatrix' for early diagnosis of PMR and GCA. The NMRF has now agreed to publish this on their website and will co-operate with each other in the future.

The aims of both these organisations is exactly the same as our aims, cause, cure and friendlier medication and support.

National

Keele University Staffordshire: The PMR Study

A team at the Arthritis Research UK Primary Care Centre at Keele University is conducting a study of the natural history of Polymyalgia Rheumatica (PMR) in primary care. They have received funding from Arthritis Research UK, via a clinician Scientist Fellowship awarded to Professor Christian Mallen, who is an academic general practitioner in our Centre. They are also working with Professor Bhaskar Dasgupta* who, as you may know, is a leading rheumatologist in the UK, and an expert in the field of PMR.

Keele has asked us for input to the proposed study and we have agreed to help in any way we can. Further information can be found on the website www.keele.ac.uk/pmr which they will be updating as the study progresses. They are also studying the attitudes of general practitioners towards PMR.

**Hon Medical Advisor to PMRGCAuk and Patron of PMR&GCA UK North East Support.*

Local

Steroid Cards

Due to changes in practices in the NHS Pharmacy Dept this project has been put on hold. The participants are in close contact and are working together to enable this project to go ahead, probably in 2012.

www.pmrangcaforumup.co.uk

Forum has 224 members including members from Australia, Malta, USA, New Zealand, Sweden and is a very active forum, with tips, hints, experiences and most of all fun.

Affiliations

We are pleased to announce that we have concluded a mutual affiliation agreement with PMRGCAuk.

Post Christmas Lunch

Gateshead members: As the Pie & Pea post-Christmas lunch was well attended, we have organised a 'Turn of the Year' buffet. The cost will be £5pp and menus will be sent to you in due course. If you wish to come, please feel free to bring family and friends. Lynne and Margaret will need your cheque and confirmation by **14 January 2012**.

Middlesborough members:

We had a very nice post-Christmas lunch at Marton Country Club last year so we have booked Wednesday 11 January 2012 at 12.30pm. Christmas fayre will be finished and normal menu will be available, ie two courses around £7-£8 TBA. The meeting will take place after the meal at 1.30pm. Please let Pam know if you are coming to the lunch by **3 January 2012**.

UK and USA Surveys

In August 2008 we launched a global online survey devised by patients from the UK and USA, which would provide data, free of charge, to patients, researchers and medics. It is hoped that it may help reveal the cause(s) of two debilitating, life-changing illnesses – PMR and GCA – which mainly affect the over 50 'Baby Boomers'. These illnesses also mainly affect women, and an estimated 100–200,000 suffer from them in the UK – and in America their 'Baby Boomer' population is estimated to include around half a million affected.

Since the survey was launched, over 500 patients have completed the survey and results are available on the website. People with PMR and GCA are urged to visit the site www.quantisurve.com/cgi-bin/pmr.asp and fill in the survey.

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