You are not alone
Polymyalgia Rheumatica and Giant Cell Arteritis

Newsletter Summer/Autumn 2012

A passionate man

Music, Medicine and PMR

My childhood was spent in a red-brick house in Jamshedpur, India, where my father, Doctor Sabitabha Dasgupta, a distinguished gynaecologist, with his wonderful musician wife Nilima, brought up their three children. In front were two large lawns where we played cricket to my mother’s constant admonishment – not to damage the plants and shrubs that lined the borders. The garden had several varieties of canna with red, orange and yellow flowers; there were vivid red hibiscus, enormous dahlias, chrysanthemums and marigolds. The verandah was draped with pink bougainvilleas and lovely madhabilata climbers – which bore delicate four-petal flowers on slim stems that delivered sweet nectar when we children sucked on them.

In addition to the floral scent, the air in our house was enriched with music and medicine. From an early age, my mother imprinted in us the melodies and rhythms of Indian classical music. My father, no mean amateur musician, trained first as an anaesthetist, then as a general surgeon and finally as an obstetrician gynaecologist. A Fellow of a few Royal Colleges, he was a President of the national Obstetrics and Gynaecology Society and edited the Society’s Recent Advances till his death. My childhood environment has had a deep influence on my later life.

The obsession with rheumatology began as a junior resident at the All India Institute of Medical Sciences in Delhi. Under the guidance of Professor Malaviya, ACR Master and doyen of Indian rheumatology, I chose not fashionable specialties but the much-neglected topic of rheumatoid arthritis to write my MD thesis. Professor Maini, the man who brought anti-TNF biologic therapy to sufferers with RA, was visiting at the time and encouraged me to come to the UK.

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My first UK position was as a medical/rheumatology registrar at Taunton under the supervision of David Yates, a kind man who helped me to gain a senior registrar post at Guys Hospital, where I had the privilege of working closely with Professor Gabriel Panayi. It was Gabriel who steered me into PMR and GCA and as ARC research fellow, we published important early papers including the first description of raised levels of interleukin-6 in PMR and GCA – perhaps presaging the day we would be able to treat these conditions effectively with a drug that suppresses interleukin-6.

Two recent events explain why PMR and GCA have been the twin faiths of my professional life. April 2012 is a proud date for PMR – it saw landmark publications on the classification criteria and assessment of patient reported outcomes in PMR. The accompanying editorial discussing the diagnosis of PMR admits that presently most clinicians cannot describe what PMR is – but they somehow know it when they see it. To me, this attitude is just not good enough – especially when it leads to long-term steroid treatment that has serious side effects.

Last week I had a heart-rending consultation with a 74-year-old lady referred from elsewhere. She had suffered polymyalgic pains for six months, unremitting jaw pain for six weeks and was referred to the Emergency department when she lost sight in one eye. She was started on high dose oral steroids but lost vision in the other eye two days later. Temporal artery biopsy showed that the internal lumen had been narrowed to a pinhole by uncontrolled inflammation. Her husband and daughter were stunned by the disaster that had suddenly undone the remaining life of their closest one.

We have made impressive progress in the last few years and PMR and GCA are now firmly on the list of serious medical challenges facing health and social care – but much work remains to be done. Our efforts must continue undiminished and we must draw level with the robust evidence base that underpins the care of other important medical conditions.

Postscript

Five years ago there was little or no research or interest in GCA or PMR, things are changing and for the better.

Since Professor Dasgupta wrote the article a major step forward has been taken and it is an important one:

June 2012

Progress on ‘Fast Track for GCA’

The National Organisation (PMRGCAuk), to which we are affiliated, advised that a meeting had been held with the Health Minister, Earl Howe.

Yesterday was a major milestone for PMRGCAuk, because we made a second visit to Whitehall to meet the Health Minister, Earl Howe. Our president, Prof Bhaskar Dasgupta, trustees Kate Gilbert and Dorothy Byrne, a member of our medical advisory panel, Brian Bourke, and Lord Wills, discussed with the minister the stunning trial results achieved by Prof Dasgupta and his team in South Essex in recent months. They managed to cut down cases of sight loss and blindness to almost zero.

How did they do this? The Southend University Hospital rheumatology team agreed with local GPs a fast-track system for referring people with suspected GCA. A GP faced with a suspected case of GCA would do a quick assessment and see whether any ‘ischaem ic’ symptoms were present, such as visual disturbance or pain in the jaw on chewing. They would phone a special number and arrange for the patient to be seen at the rheumatology clinic on the same day, and given intravenous steroids. Other cases would be seen within 24 hours. Advice to GPs recommended that the patient be started on prednisolone even before going to the hospital. This won’t interfere with the results of any biopsy as long as the biopsy is carried out quickly. If the patient turns out, on the decision of the rheumatologist, not to have GCA after all, the steroids can be stopped without any danger to the patient.

We believe that when faced with a suspected GCA case, many GPs are in a dilemma because they know that the patient needs steroids but they are worried that putting them on steroids will mess up the diagnosis. And this is often the case when it may be weeks rather than days before that patient gets to see a specialist. And we know that it is that delay that causes many people to go blind in one eye, and in the worst cases go blind in both eyes.

If GCA can be treated on a fast-track pathway like this, so that GPs can be confident that they can give the steroids and the patient will be seen straight away, they will have no fear about doing what has to be done. The fast track is a perfect example of primary and secondary care working together properly.

So what we want is to see this pilot study turned into a model that can be rolled out across the country. The Department of Health is sympathetic to what we are saying. They agree with the figures – GCA is affecting the eyesight of about 3,000 people a year who are losing vision to some extent. Of these, about 1,000 are losing
Medical talks at University Hospitals

Pam Hildreth, Secretary, has been talking to medical students in her local university hospital (Sir James Cook) for the past four years.

The Medical students are generally in their third year and spending some time on rheumatology as part of the curriculum.

In the early years, it was very rare for any of the students to have heard of PMR and, in fact, none had heard of GCA.

Pam supplied them with handouts, consisting of Professor Bhaskar Dasgupta’s guidelines for management of PMR and GCA, a list of useful websites, and stressed the importance of early diagnosis of GCA (this frightened them – but that was the idea!).

Later, when we (PMR&GCA UK North East Support) produced our DVD You Are Not Alone, a free copy was also included in the package.

This year (2012), for the first time, the students are receiving a lecture on PMR and GCA before they see me. This is brilliant news. They already know about the illnesses and go on to ask about symptoms, treatment and side effects.

To help educate future GPs about PMR and GCA, would our members volunteer for this work as patient representatives? It is only three afternoons per year and expenses are paid. There are 31 University hospitals in the UK. They have academic centres which arrange these sessions under the instructions of Consultant Rheumatologists.

If anyone is interested, Pam is happy to make enquiries on your behalf. Please let us know where you are located and if you are PMR, GCA or both.

July 2012

We watched the space, and this is the outcome

Dear Friends

We are excited and absolutely thrilled to let you know that, following our meeting 10 days ago at the Department of Health, department officials have today agreed, with the blessing of the minister Lord Howe, to participate with Professor Bhaskar Dasgupta and ourselves in a working group to evaluate the pilot of a fast-track route to GCA diagnosis, to avoid sight loss.

b) if it is shown to be effective, to work on a model and a process for disseminating it around the UK.

This undertaking is the fruit of a long and persistent campaign by Lord Wills of Swindon to get the DoH to take seriously the risk of sight loss due to the misdiagnosis or the late diagnosis of GCA. It started a year ago last March, with a debate in the House of Lords, and we hope that by next March the working group will have made enough progress to hand a fully worked-up model to the new Commissioning Boards.

Clearly we will let you have more information about the composition of this group and its terms of reference in due course, but enough at the moment to say that it will include representatives from the Royal College of GPs, the British Society of Rheumatologists, senior Whitehall staff, a patient representative, as well as PMRGCAuk.

Nothing like getting in at the grass roots and shedding some light.
Middlesbrough Area 1 News

January
A post-Christmas Lunch was held in the Marton Country Club, followed by a short informal meeting.

March
Annual General Meeting – there was no change to the Officers and a short financial report was made. The Guest Speaker was Robin Ramsey of Wills & Probate. The talk was interesting and informative and, although it was a serious subject, there was much laughter and the Group thanked him for his excellent presentation.

June
Lynne Boyle, Trustee & Membership Secretary. In the absence of Carol Suffell, Lynne would deal with the register and membership queries. The Guest Speaker was Sarah Smith from ‘Yellow Card’ scheme.

Sarah handed out leaflets about the scheme with forms inside on which to report side effects. These should be available from any chemist free of charge.

Following the presentation, a question-and-answer session was held. The group thanked Sarah for attending and giving us an interesting presentation.

Pam was delighted to inform members that the group had been awarded £300 to help with running costs from the Middlesbrough & Teesside Philanthropic Foundation. These funds were for Middlesbrough only.

The raffle, run by Phil and Ron, raised £48.10p.

Members were thanked for bringing old DVDs and CDs which would be sold and for bringing old spectacles to support another charity which forwards them for use in India.

Member Ken Bolton brought copies of his poetry book Kismet – given free, but in the hope that people will support Teesside Hospice and the Salvation Army.

Gateshead Area 2 News

January
Gateshead Group held their New Year’s Celebration Buffet in the Caedman Hall, Gateshead Library. Members travelled from as far as Carlisle to attend. We were joined by Edward Gainford of GDA Design, who has been a great supporter of our charity, Dr. V Saravanan Consultant Rheumatologist and Nichola Scholes Acupuncturist. The buffet was judged a success by those attending. There was one piece of good news, The Chair Mavis Smith informed the meeting that her GCA was now in remission and she was free of steroids. This had been confirmed by the use of a machine, which was currently taking part in the TABUL research study and this study was due to end in April 2012.

March
After a short AGM we were delighted to welcome Lisa Green from Gateshead Council Adult Social Care Directorate. Lisa explained the support Gateshead Adult Social Care Directorate can give to people with disabilities and handed out contact details. These details were also placed on the website, as Lisa supplied a list with contact numbers for most of the rest of the North East.

On 19 March, Margaret Wright was invited to give a short talk about our charity on Radio Washington, an internet radio station.
On 24 March, four of the Trustees travelled to London to a Support Group Organisers meeting held by the National Charity PMRGCAuk, to whom we are affiliated. Here, we were able to meet other Support Group Organisers and Trustees of the National Charity to share best practice and look at ways the National Charity can help Support Groups. It was a very long day, we left Newcastle at 7am and returned at 10pm. We were all exhausted but found the day very informative.

June
Guest Speaker – Sister Jackie Binding, Rheumatology Nurse, based at the Queen Elizabeth Hospital, Gateshead.
Jackie gave an illuminating talk on the use of Methotrexate in Rheumatoid Arthritis. Jackie explained that Methotrexate was the ‘gold standard’ drug for RA sufferers. Apart from her full-time position, Jackie is Vice President of ARC in the North East and also assists in the running of a support group for NRAS.

After Jackie had made her presentation, she held an individual question-and-answer session for members who wished to ask specific questions. The members thanked Jackie for her time and interest.

Another Guest Speaker came from Wiltshire Farms Foods (see the article in this Newsletter).

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

**PMR-GCA Scotland: Jean Miller is Retiring**

We received a letter from Jean as follows:

Dear All
It is with no regret that I tender my resignation as Chair of PMR-GCA Scotland, with effect from 17/07/12. I have loved every minute of my term as Chair but because of a relapse of PMR & GCA and age (77), I am no longer able to fulfil the role effectively.

We are so fortunate that Bea Nicholson has agreed to take on the role of Chair. I know she will bring vision, vibrancy and a sincere dedication to the role and look forward to seeing the development and expansion of the work of PMR-GCA Scotland. I was very touched to be asked to be a patron of PMR-GCA Scotland. As you all know, I am passionate about the diagnosis, care and treatment, but above all the support, of people with PMR & GCA.

I am very happy to continue my interest by remaining as a trustee and a member of the helpline team. With sincere thanks to you all for all your support.

Jean Miller.

Well Jean’s retirement it not complete as Jean will still answer calls from people who are seeking help for the above conditions as she always has done.

I first came into contact with Jean, when I was diagnosed with GCA and desperate to speak to someone who knew about GCA, without Jean my first six months would have been much worse. Jean Miller had set up PMR & GCA Support in March 2006 after having had PMR & GCA for 4.5 years and of searching unsuccessfully on the web and elsewhere for help, support and information. You can imagine how difficult it has been for her over the years.

Against all adversity, she has succeeded in seeing her visions come to fruition.

In March 2008, Jean was one of the group of people who attended a landmark meeting with Professor Bhaskar Dasgupta in London. This was the first time that Pam Hildreth and myself actually met Jean Miller. Jean was a driving force in setting up not only her own Scottish Charity PMR-GCA Scotland, but the National Charity PMRGCAuk as well. Jean also served as Trustee of PMRGCAuk.

However, Jean’s health has forced her to stand down as Chair of the Scottish Charity and she is delighted to hand over the roll to Bea Nicholson.

Bea is well known to the Trustees of our charity and has given us invaluable help in the past. Jean will be a hard act to follow but we have every confidence Bea will drive the Scottish Charity from strength to strength.

Jean has been a close friend of PMR&GCA UK North East and her advice and support has been invaluable to us all. I am sure you will all join the North East Trustees in wishing Jean our best wishes for the future.

Mavis R Smith Chair

Gateshead next meeting

**Monday 24 September 1.30pm**
Gateshead Library, Prince Consort Road, Gateshead

Guest Speaker – Amy Duguid, Physiotherapist, Queen Elizabeth Hospital, Gateshead

Photo: © Bea Nicholson
When a stiff jaw means you’re losing your sight

Extract from an article, first published in the Daily Mail on 16 July 2012 by Dorothy Byrne

Ken Bolton’s problems began when he sat down to eat his lunch one day and found he couldn’t open his mouth. ‘My jaws were just stuck,’ says Ken, 78, from Middlesbrough.

As he didn’t feel ill, he avoided solid food. But after two weeks with no sign of improvement, he went to his GP, who suggested seeing a dentist. The dentist could find nothing wrong, so referred him to a hospital dentist.

Meanwhile, Ken began to lose his sight for a few minutes at a time. His optician reassured him there was nothing to worry about.

However, a few days later, Ken went blind in his right eye three times in one morning. He went to A&E where he was examined but advised to wait for another hospital appointment a few days later.

Increasingly concerned, Ken started to keep a diary of his symptoms. Over the next four days, he went blind 35 times. His GP diagnosed a mild stroke, wrote a prescription for a large dose of aspirin and arranged another hospital appointment.

As soon as he walked into his house, Ken went temporarily blind in both eyes.

When he finally saw the hospital dentist, he suggested Ken’s stiff jaw was due to a problem with his dentures.

Five weeks after his ‘stroke’, Ken was seen by a consultant. ‘She had all my medical notes and I don’t think she was convinced I was ill,’ he recalls. ‘So I got out the diary.’

The consultant took one look at it and told Ken he needed treatment urgently. For Ken had giant cell arteritis (GCA), inflammation of the arteries which supply the head; this then blocks the blood supply to the optic nerve. Key symptoms include sudden blurred vision, painful headaches, a stiff jaw and a very tender scalp.

Blind? Ken’s optician said his sight problems were nothing to worry about.

As head of News and Current Affairs at Channel 4, I am used to covering stories about people getting terrible, preventable diseases in developing countries, but it horrifies me that so many people in Britain are going blind unnecessarily.

What’s so surprising is it’s not just GPs who are getting it wrong; doctors in A&E, even hospital eye clinics, are failing to spot symptoms.

Barry Peck, a former office worker from Nunthorpe, Middlesbrough, used to love cycling in the countryside. Now he cycles in a shed to keep fit on a bike adapted by his family. He is virtually blind after doctors failed to realise he had GCA.

What is remarkable about Barry’s case is he was so ill he was hospitalised with symptoms that included several signs of GCA — as well as double and blurred vision, he had a severe headache and a sensitive scalp.

He was seen by an ophthalmologist, but after three days, Barry, 75, was sent home, diagnosed with facial cellulitis (a deep skin infection in the face). ‘He went home and lay down on his bed in the dark with the most terrible headaches,’ says his wife Brenda.

After two days, Barry was taken back to A&E and finally GCA was diagnosed, but by then most of his sight was gone for good. He can now see only people’s outlines and needs constant guidance outside.

If doctors recognise the symptoms, the outcome can be so different. Hannah Padbury, from Thorpe Bay, in Southend, runs a local helpline for Polymyalgia Rheumatica and Giant Cell Arteritis UK, the charity which campaigns for people with the condition. When she herself developed a stiff jaw and eye problems, her GCA was diagnosed quickly by her hospital rheumatology department and she was given steroid infusions.

‘I hear lots of stories which horrify me. One lady had done everything to try to get help but ended up losing the sight in one eye. Doctors need to be far more informed.’

By an extraordinary coincidence, I was at a meeting of the charity’s trustees when a helpline call came in from a woman who’d gone to a leading London hospital having gone blind in one eye. The hospital said her blindness was caused by GCA, but it was too late to do anything. Yet without treatment, the woman could have gone blind in the other eye, so the helpline told her to go to another hospital and demand treatment.

All it can take to stop someone going blind is 60 milligrams of prednisolone – that’s around £1.20 to stop a life being wrecked and many tens of thousands being spent to support someone who has gone blind.

Dorothy Byrne is Head of News and Current Affairs at Channel 4 and a Trustee of PMR GCA UK. Dorothy was diagnosed with GCA two years ago and is tireless in her efforts to raise awareness.
Raising funds

We are constantly seeking funding and ways of raising funds for support and research.

We opened a little shop on our website and our first item for sale is our:

Pansy badge/tie tin

Why a Pansy?
The legend of the pansy tells that the flower was originally white and blushed bright purple when it was pierced in the middle by Cupid’s Arrow. It was used to send thoughts of love to your fellow men.

‘I had suffered from PMR for over two years. I was so ill and struggling to cope, my poor family just could not get their heads round this totally different person in their lives. I felt so isolated and alone and didn’t know anyone who had PMR. Then I heard about Pam Hildreth and Mavis Smith and their efforts to set up a support group. After a long talk with Mavis, she emailed me with more information to help me understand the condition and treatment – in the background of that email was a pansy, I don’t know why or how, but when I saw the pansy it brought me so much hope and I felt that at last someone understood and ‘I Was Not Alone.’

When we looked for a logo for our support groups we decided to use the pansy hoping that the symbol would bring hope and comfort to others. So please buy and wear your pansy, give one as a gift to others so that when people ask what it represents tell them, it will raise awareness of these two conditions and pass on the word we and others are here to help. The profit will all go towards our work to support patients and to seek cause, cure and friendlier medication for PMR & GCA.

Margaret Wright.

The pin badge/tie pin cost £1 each

If you order by post, sorry but we will have to charge an extra 50p for the first badge (£1.50) and £1 for each extra one you order in the same package. For an extra 25p, why not buy a gift bag for your pansy badge (no extra charge for postage). For an order form, you can either visit the website

www.pmr-gca-northeast.org.uk

or contact us by email

pmrgcafightersne@googlemail.com.

easyfundraising on the internet

We have joined easyfundraising and this is how you can help us. Easyfundraising is a member of the Institute of Fundraising. They raise millions of pounds for good causes across the UK, there is no catch.

How it works: Easyfundraising is the simplest way to raise funds for your good cause. You shop online and you raise money at the same time. It’s that easy. Easyfundraising works with well-known retailers such as M&S, Argos, RAC, etc. Once you have registered, each time you purchase from those retailers in the scheme they will donate a percentage of the money to us.

It costs you nothing. What’s more, they will find voucher codes and discounts so you can save money on your shopping too.

Registering:
1. Your unique easyfundraising URL is

www.easyfundraising.org.uk/causes/pmrgcauk

This is the link you should give to your supporters when you ask them to register with us to support you.

2. When you’re ready to shop simply click on the retailer you want, then shop as you would normally. When you make a purchase, easyfundraising will send you an email telling you how much you’ve raised and pass the donation on to us. And that’s it!

How much can my purchases raise? Donations vary between retailers but an average donation is 5% of your spend. Some insurance and mobile retailers pay a substantial one-off of up to £50. The donation amount is shown directly next to each retailer listing and we will receive 100% of the donation shown.

Am I buying from the retailer or easyfundraising? YES – you are still dealing directly with each retailer. For further information visit

www.easyfundraising.org.uk

Please email us and let us know you have joined to help us help you

pmrgcafightersne@googlemail.com.

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
Lynne Boyle

Lynne, who is a Trustee and our Membership Secretary, has been appointed as a Trustee to PMRGCAuk, the National Organisation.

Lynne has had PMR for six years and recently retired from the insurance industry. Lynne can now devote more time to our charity and will be a valuable asset to the National Charity. Lynne still plays squash although she concedes her best days have passed!

A gift from a bride, a groom and a church

Ron and I have known the Pendlington family since they moved two doors up from us over 20 years ago. We have watched, with pride and affection, young Mark, Elaine and Lindsey growing into such wonderful young people of whom any parent would be proud. We were very touched when Lindsey and her fiancé, Mike Weightman, made our charity their nominated charity on their wedding day at St George’s Church, Cullercoats, Tyne and Wear on 30 June 2012.

St George’s has a tradition that, when anyone is ‘hatched, matched or dispatched’, the collection taken after the service is divided between the Church and a Charity nominated by the family. It was a fairytale wedding, a wonderful day and I am sure all our members will join the Trustees in wishing Lindsey and Mike their best wishes for a life full of joy and happiness.

Margaret Wright
Vice Chair PMR&GCA UK North East Support

Tips and Tricks for PMR

- If your scalp hurts, run your fingers upwards through your hair two or three times.
- Each individual hair has a muscle attached to it, think how sometimes the hairs on your arm stand up.
- As PMR is muscular, the hair muscles can ache. The simple action of running your fingers upwards gently can relieve some scalp pain.

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After the heavy snow falls and icy roads in winter 2010, we awaited another drastic winter in 2011. However, we were lucky to escape with little snow, but many icy days. Some members were finding it difficult with the icy roads to leave their homes, so we decided to see how we could help, perhaps with a home meals delivery service.

Wiltshire Farm Foods

Our second Guest Speaker at our meeting on 25 June was Mr Harry Charlton, Business Development Manager from Wiltshire Farm Foods, a home meals delivery service franchise based in Gateshead. Harry explained that Wiltshire Farm Foods had been going for over 21 years nationwide. The franchise in Gateshead had been taken over by Mr Steve Arkley last year, and now had a team of dedicated staff to deal with orders that could be taken over the phone, or collected by the home delivery drivers.

He explained all delivery drivers are police checked and will carry the food into the house if required. The delivery service is on the same day each week, for each area and customers are given a timescale within an hour, depending on road traffic conditions, when the delivery will be made. They have 250 tasty dishes on offer and also a ‘Customer Favourite Pack’ of 6 main meals and 4 desserts for £29.95, so you can try it for one week. They also carry a beautiful presented Soft and Pureed range and cater for diabetics.

For those people living in Gateshead, Northumberland and surrounding areas, please contact 0191 263 5599 if you are not in their franchise area. For areas outside the Tyne and Wear area, please contact 0800 773 773.

It may be something to think about for the forthcoming winter.