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Members' Day 2018

More than 80 people from around the UK joined us on September 8th for our annual Members' Day and AGM to hear about the latest research into PMR & GCA, meet others with the condition and share their stories.

See inside for highlights from Members' Day, including:

- The significant increase in research in PMR and GCA
- A tribute to the visionaries who set up PMRGCAuk
- Your chance to get involved in research



NEW PHONE BUDDY SYSTEM

A new PMRGCAuk initiative, a 'phone buddy' system, is being mapped out currently, with the aim of providing help and support to members who can't get to their nearest group or who may be too frail. It will take time to develop this, finding and training volunteers to act as 'buddies' and putting them in touch with those who would most value the service. We were delighted to receive a grant of £750 from the Ann Rylands fund of the Sir Jules Thorn Charitable Trust to set us on our way.

 **NATIONAL
HELP LINE**
0300 111 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.

Save the dates!

PMRGCAuk WEEK: 18-24 JUNE 2019

With the 2019 PMRGCAuk fundraising week dates just announced, now is the time to start planning. Look out for more information on our website soon at www.pmrzca.org.uk - and tell us about events you have planned.

MEMBERS' DAY: SATURDAY 7 SEPTEMBER 2019



'Enormously exciting times'

Welcome to our new Chair

"It is extraordinary how unrecognised the conditions PMR and GCA are but the potential developments in treatment are 'enormously exciting'. And members of PMRGCAuk have a key role to play in advancing understanding and research."

These are some of the thoughts of the new chairman of PMRGCAuk Professor Humphrey Hodgson, who recently retired from the prestigious Dame Sheila Sherlock Professorship of Medicine at University College London Medical School.

Sheffield-born, but brought up in London, Humphrey has held a number of leading medical posts including Professor of Gastroenterology and Professor of Medicine at Hammersmith Hospital, and Campus Dean at the Royal Free Hospital. He has led cutting edge research into chronic diseases of the gut and immune diseases of the liver and is still involved in research into the creation of an artificial liver machine. He has been a Trustee of the British Liver Trust and it was there that he realised the great benefits of a patient-oriented charity.

'Empowering patients with immune diseases who I was caring for was key. Increasingly, patients wish to take control of their own destiny.'

'When I learned about the work of PMRGCAuk, I felt I could bring my experience to bear. If you have spent your whole life in service, you want to continue to give service.'

He is impressed by the charity's work, 'It's full of very dedicated people.'

But he is aware of the challenges, the first being funding. 'It is a very small hand-to-mouth organisation and raising funds is a key issue. But just as important is supporting our

volunteers and the individual groups and maintaining their enthusiasm.'

Humphrey has joined with our President Professor Bhaskar Dasgupta to organise a major British Medical Association webinar which should reach 1,000 GPs.

He sees educating GPs and the public as vital to progress. 'It is an extraordinary thing that these conditions are so unrecognised, yet they are very common. They need advocates.'

He is shocked by the tragic stories he hears of patients who didn't get the right treatment. 'When you hear of sudden blindness because, while the GP knew the patient had GCA, the right treatment was not given, it's heart breaking.'

However, he also emphasises positive developments. 'There are enormously exciting new treatments which will roll out over decades. They are expensive now but the price will come down hugely.'

Humphrey thinks the charity can play a key role in supporting research as many patients are keen to be involved. He points to the possibilities of patients being involved in genetic research. 'A simple genetic survey can be extraordinarily effective, looking at the genetic make-up of family members who are affected and comparing with those unaffected. The possibility of developing a specific diagnostic test for these conditions exists which would be a great step forward.'



NEW DIRECTOR AND DEPUTY DIRECTOR JOIN US

Liora Ives joined as new Director of PMRGCAuk in August. With a background in education and the charity sector, she brings experience in marketing, communication and fundraising.

'We need to reach out to more people – many are diagnosed each year that are unaware of the information and support we can offer. It's so valuable to connect with others in the same position and to have access to information about managing your condition, as well as future treatment options and the latest research. As we celebrate our 10 year anniversary, I'm looking forward to building on the successes of our small staff team, trustees and volunteers.'

She is joined by Candy Horsbrugh as Deputy Director, who brings experience of working with community groups and transforming the future of small charities. 'So much has been achieved, but there is a lot to do to raise awareness and fundraise sustainably. I look forward to helping to do this to ensure we continue to offer an excellent service.'



RESEARCH ROUND UP

Dr Sara Muller is a Research Fellow at Keele University, where she leads the PMR Cohort study.

Whilst they have some way to go before they are likely to be used in routine clinical care, researchers are considering the use of CT¹, PET² and ultrasound³ scans.

There is also some more 'up-stream' research being conducted to try and identify sub-types of GCA based on symptoms, response to steroids, scan results, types of cells on biopsy and more. This may help to make treatment more personalised (for example⁴), but it will be a long way into the future.

I know there is much interest in the use of tocilizumab to treat GCA. There have been a couple of studies recently that have looked at its use. One study re-analysed trial data to look at markers of inflammation in the blood⁵. They concluded that there is still work to do on the optimum way Tocilizumab might be used to treat GCA. They say that it needs to be a combination with steroids, and that at least 52 weeks of treatment is likely to be needed. In contrast, another study suggested that Tocilizumab could be used as a short term treatment to reduce the total amount of steroids needed⁶, whilst a third,

very small study, highlighted the need for careful monitoring of people taking tocilizumab in case of adverse reactions to the treatment⁷. A further study has suggested the potential use of Leflunomide to reduce the amount of steroids needed in GCA⁸. Clearly there is still some way to go to find an alternative to steroids that can be widely used.

Tocilizumab has also been evaluated recently for the treatment of PMR⁹. The authors of this study suggested that whilst it will be worth investigating this treatment for people whose PMR is not well-treated by steroids alone, it does not entirely treat the inflammation, and so could not, at the moment, be recommended as a replacement for steroids.

A group of researchers from Italy noticed that doctors had reported cases of people with PMR having a bowel condition called diverticular disease¹⁰. They set up a study to look at this more closely and found that people with PMR were around 4 times as likely to have been diagnosed with this condition before they were diagnosed with PMR – on average around 7 years before. This might help us to understand something about the causes of PMR, related to changes in the microbial make-up of the gut.

Finally, you can also access our write up of last year's membership survey, particularly highlighting areas

you said should be research priorities here: <https://link.springer.com/article/10.1007%2Fs10067-018-4220-1>

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ACROSS THE COUNTRY

CHICHESTER GROUP

A Bring and Buy sale was held at the summer meeting as part of PMRGCAuk Week, raising £52.

EAST MIDLANDS GROUP

A practical session was led by physiotherapist Annabel Kingsbury, who specialises in Neurology and Rehabilitation. She gave the group "A bunch of fives" – ideas to exercise the 5 areas of the body (head and neck, upper body and shoulders, arms, lower body and pelvis, and legs and feet) to work on the 5 core areas of flexibility, balance, strength, stamina and posture.

NEW GROUP!

HARLOW GROUP

A new group has been set up, with two meetings already under their belt and with access to a mini bus they hope to arrange outings in the future. Contact Jean and Julie at harlow@pmrgca.org.uk

NEW GROUP!

HARROW/PINNER GROUP

Are there any members in the Harrow area of London who would like to join a new group? Our first meeting is on Thursday 22nd November at 11.30am in the United Service Club in Pinner. For more information contact Jennifer at pinner@pmrgca.org.uk.

ILKLEY GROUP

Sue Hargreaves, organiser of the Ilkley Group was delighted to get leaflets into a doctors' surgery following a

Healthy Living event. The GP who attended the event said she saw quite a few cases of PMR, but knew nothing about the charity and the support available, showing just how vital these events can be in helping to raise awareness.



LONDON GROUP

Leading rheumatologist Professor Margaret Callan spoke to the group on new approaches to treating Giant Cell Arteritis. They heard that clinical trials indicate that addition of methotrexate to steroids reduces the risk of a first relapse by 35% and a second relapse by 50%. 'Until very recently our options in treating GCA were very limited. Now we are using our understanding of the disease to develop targeted treatments as an addition or alternative to steroids.'

Tocilizumab (TCZ), a drug used extensively for people with rheumatoid arthritis, is now approved by NICE for treatment of GCA if the condition does not respond to steroids (refractory disease) or flares after steroid treatment (relapsing disease). However, a year's treatment with TCZ costs the NHS almost

£12,000 per patient. Currently its use within the NHS is restricted to one year's treatment for people with refractory or relapsing GCA. Professor Callan commented that 'this is likely to change in the future'. Other 'biologic' drugs with actions similar to TCZ are being developed and treatment costs will probably fall.

Professor Callan also told the group that the latest thinking is that there is a genetic predisposition involved in developing GCA and variants in genes have been identified.

ORPINGTON GROUP

At their September meeting the group learned about type 2 diabetes, which can be caused by prolonged use of steroids. Richard Lane, OBE, Immediate Past President of DiabetesUK, spoke about the need to make sure that feet are part of the annual NHS check-up with your GP as they can be an early indicator of diabetes. The group presented a cheque to Richard who will be requesting that it is put towards a research project closely connected with PMR and GCA.



Richard Lane, OBE receiving a cheque from Orpington Support Group organiser, Penny Denby (Photo: Rob Lawrie)

PORT SOLENT

A raffle held in June raised £82 and Barbara Winspear was delighted to receive the cheque at a recent Osteo event at Hill Head.



Barbara Winspear receiving a cheque from Colin Beavor.

SHROPSHIRE GROUP

Our thanks to David and Kath Davies for running the Shropshire group so well for many years after recently stepping down. The group now have a small new team of volunteers who will be providing support in Shropshire. Email shropshire@pmrgca.org.uk.

TAUNTON GROUP

The Red Cross led a session at The Taunton Group meeting helping to increase confidence in dealing with head injury, broken bones, heavy bleeding, stroke and heart attacks, to name a few.

NORTHERN GROUPS

Can you help set up a group? We are particularly keen to have more groups in the North of England and would love to hear from you. We will offer advice and support to help you to set up the group and there is a full Group Organisers pack available.

Please get in touch with candy@pmrgca.org.uk



MEMBERS' DAY 2018

Guest speaker highlights

'Good that so many dynamic and dedicated people – medical and otherwise – are involved in understanding and finding treatments for the two conditions.'

Members' Day delegate

MAJOR RESEARCH INTO PMR AND GCA

Dr Charlotte Harden

Members of PMRGCAuk are offered the chance to help in a major research programme into GCA which aims to reduce steroid toxicity, find replacements and improve the outcomes of GCA patients. 'We need the experiences, perspectives and ideas of patients', Dr Charlotte Harden of the Treatment According to Response in GCA (TARGET) project told the charity's AGM in a keynote speech.

The project aims to share data from all trials involving people taking steroids for GCA and place biological samples of blood and urine in a biobank. This data will be used for research and to facilitate projects to get additional funding for new research into GCA. Key issues examined will be how the disease develops, risk factors, symptoms,

better diagnosis, how people get treatment, the progression of the disease, how patients are monitored, steroid toxicity, the repurposing of drugs used for other conditions and how to engage patients.

Dr Harden highlighted the problems of lack of awareness and knowledge about the conditions. Researchers want to know whether, for example, there are genetic tests which could be developed.

Can you help?

Researchers want to know more about patients' experience of side effects of steroids as well as experience of getting diagnosis in the first place. Contact Dr Harden at c.j.harden@leeds.ac.uk



MEMBERS' DAY 2018 GUEST SPEAKER HIGHLIGHTS

CELEBRATING OUR TENTH ANNIVERSARY

Professor Bhaskar Dasgupta & Kate Gilbert

It began with five women 'The PMR Fighters' backed by Professor Bhaskar Dasgupta and groups in East Anglia and Scotland. Ten years on, PMRGCAuk is the only dedicated UK charity and helps anyone affected by PMR and GCA. It has over 900 members and in the last year supported more than 7,000 people online.

'I posted in a moment of sheer frustration. I couldn't believe I had an illness there was no organisation for,' founder member Kate Gilbert told the AGM. Now the charity supports patients in many ways, including a helpline, a network of local groups and online information, as well as raising public awareness, educating GPs, successfully campaigning for better treatment and backing research.

Professor Dasgupta paid tribute to the 'visionaries' who set up the charity. He thanked Lord Wills for his support in the House of Lords and with lobbying ministers. He urged patient groups to pressurise hospitals to make available vascular ultrasound for early diagnosis. 'We need to ensure guidelines and standards of care are implemented in practice.' He revealed devastating consequences for two of his patients who lost sight.

Kate described the increase in the charity's activities as 'a phenomenon' but warned that more donations were needed. 'We need more funds to support the huge surge in the help we are giving so that we don't collapse under the weight of expectation and need,' she said.

If you would like to donate to support our work please visit www.pmrzca.org.uk to donate via Virgin Money Giving.



RESEARCH INTO PMR AND GCA – WHAT NEXT?

Dr Sarah Mackie

Dr Sarah Mackie, rheumatologist and Patron of PMRGCAuk spoke about the significant increase in research into and medical publications citing PMR and GCA.

Tocilizumab (TCZ), has been approved by the National Institute for Health and Care Excellence (NICE) for patients with relapsing or refractory GCA and there are five other trials registered in the world for alternatives. Like Tocilizumab, most of these drugs are defined as biologics, which means that their design is based on molecules the body itself makes as part of the immune response. Generally biologic drugs are given by injection.

There are plans for trials of Sarilumab recruiting 360 patients, Anakinra recruiting 70 patients and Mavrilimumab recruiting 60 patients. There are early stage trials of Ustekinumab (20 people) and Baricitinib (15). Baricitinib isn't strictly a biologic drug but a "small molecule inhibitor" which is given in tablet form.

Dr Mackie warned that it can take many years before a drug accumulates enough clinical trial evidence to allow it to be licensed. In England there is a further hurdle to clear in that NICE must approve its use before NHS use can be agreed.



THE LIGHTER SIDE...

Mark Benjamin

Many users of Health Unlocked will know Mark Benjamin's humorous musings on his PMR and they got a chance to meet him in person when he addressed the AGM. Now symptom free and on only 2mg of prednisolone Mark spoke for many when he said, 'The learning journey is a maze. You are picking your way through how to find the right information and what to do. There's so much that we can't anticipate.'

He said he had learned a few things along the way: put yourself first, realise you can't have control, be flexible, pace yourself and relax and accept there is still no definite information. 'It's perfectly natural to get depressed with these illnesses. It's a difficult emotional journey.'

Mark's book, Write Me Funny, is available from the PMRGCAuk website, www.pmrzca.co.uk/content/book

A donation is received by PMRGCAuk for every copy sold.

'(a good) opportunity to listen to such well informed and entertaining speakers. To share experience of PMR. To speak to some very knowledgeable people.'

Members' Day delegate

Save the date for the next Members' Day
Saturday 7th September 2019

Lorna Neill, Chair of PMR GCA Scotland news round up...

HIGHLAND GROUP A SUCCESS

Only a year ago David Carrott from Nethybridge restarted a PMR-GCA Scotland support group which would meet in Inverness and serve members who could reach the city from the surrounding area. Meeting monthly they have had a great year and in August were host to a physio and occupational therapist from NHS Dingwall who spoke to the group and provided a really useful set of tips for undertaking everyday activities based on the 4Ps – prioritising, planning, pacing and posture. We hope to make these available on the website if permission is given. See our website for meeting dates and details.

GCA DIAGNOSIS AND TREATMENT – TWO GREAT RESULTS...

For the last three years the charity has had the aim of raising awareness of GCA amongst clinicians and the public, encouraging the adoption of Fast Track diagnosis where possible throughout the country and supporting ultrasound scanning to help confirm diagnosis and minimise the need for temporal artery biopsy. In 2016 we started by running a conference for health care professionals in Glasgow at which Professor Dasgupta and Clinical Nurse Specialist Madeline Whitlock described the best practice that had won a BSR Award at Southend.

Since then, with the previously described help of Fife rheumatologists, a prolonged campaign through the Cross Party Group on Musculo-skeletal Conditions at the Scottish Parliament and an interchange of letters with two

Ministers has resulted in us receiving a very detailed and supportive letter from Joe FitzPatrick MSP, Minister for Public Health and Sport. The Fife Pathway for GCA has been fed back to the national Short Life Working Group on systemic vasculitis (GCA is the commonest large vessel vasculitis) as an example of good practice and a national group that provides strategic direction to National Diagnostic Networks has been asked to consider the ultrasound component of the Fife Pathway further.

GCA ultrasound

We are now pleased to report that a donation to the charity is being used to support training in GCA ultrasound for two new consultants, one in Fife and one in Lanarkshire.

The Scottish Medicines Consortium accepts Tocilizumab for adult patients with GCA

The news that the SMC has accepted Tocilizumab for treatment of adult patients was made public on 10th September. Lorna Neill said, "This is great news. Many thanks to all the members who contributed to the submission. Patients' views, often in their own words, were received very well both from the written submission and when I attended SMC meetings and was invited to speak on your behalf. I am sure they influenced those making the decision.' Full details can be found on the website, where there are also links to the SMC website with full details of the PMR-GCA Scotland submission.

Lorna continued, "The only restriction placed on use of the drug in Scotland is that it is time-limited to one year. If your doctor suggests trying this new treatment do remember that it is used in conjunction with steroids not instead of them, that it is not suitable for



HELPLINE

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www.pmrangca.org.uk

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SC037780

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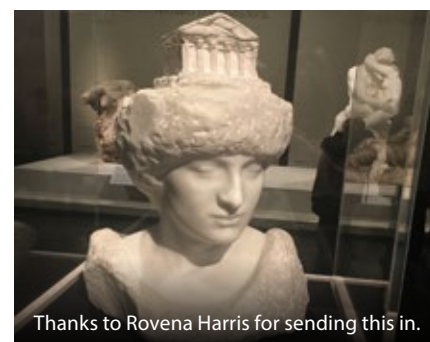
everyone because, like all powerful and effective medications, it has side effects in some people and it is very expensive (the NHS pays). It can however shorten the time to steroid-free remission and lower the overall dose of steroids taken to do this and is a very welcome addition to the treatment options for GCA."

ADVANCE NOTICE

The 2019 AGM will be in The Studio, 67 Hope St. Glasgow on Friday 12th April.

Speakers will be Kate Gilbert, author of Polymyalgia Rheumatica and Giant Cell Arteritis – a Survival Guide and Mayrine Fraser of the National Osteoporosis Society.

COULD THIS BE THE FIRST RECORDED EXAMPLE OF TEMPLE ARTERITIS?



Thanks to Rovena Harris for sending this in.



Interview with the President of the British Society for Rheumatology

Keen to co-operate with the BSR to further the interests of patients, we were delighted to interview Dr Liz Price, President of the British Society for Rheumatology, the key body for rheumatologists.

BSR represents health professionals working in rheumatology and has 2,500 members. While most members are consultants, it recently merged with the body representing other health professionals specialising in this area such as physiotherapists and nurses. Dr Price has seen changes over the years in how patients with chronic rheumatological conditions like PMR and GCA are treated. Today the approach is multi-disciplinary and collaborative, with patients themselves playing an important role.

"Patients are now better informed; you have to be prepared to go on a journey with them.

Over the last three to four decades we have seen the increasing influence of patients. We make decisions with patients, not for them. We are collaborative and inform them about their conditions and discuss side effects of drugs."

The Royal College recommends that there should be 1.09 consultant rheumatologists per 100,000 people. Currently the figure is 0.86 per 100,000 but distribution is not even. Wales is served comparatively well

Number of consultants and specialist nurses per 100,000 by NHS region and Wales

Region	Catchment population	Total number of consultants	Consultants per 100,000 population	Total number of specialist nurses	Nurses per 100,000 population
National	57,931,083	498	0.86	382	0.66
London	8,859,689	75	0.84	41	0.47
Midlands & East of England	15,226,195	138	0.90	107	0.70
North of England	17,100,757	152	0.89	131	0.77
South of England	14,034,442	102	0.72	76	0.54
Wales	2,710,000	32	1.18	26	0.95

but South of England and London don't fare so well. More medical students are now entering the system but it takes 10-15 years to train them. She highlights the important role played by rheumatology nurse specialists but says, 'Most units have to train their own specialist nurses and this might take a year.'

Consultant rheumatologists see only the complex PMR cases in which patients have not responded to their drug treatment. Dr Price explains some of the reasons why GCA can be hard to diagnose. 'Patients don't always follow the text book. I remember as a junior doctor seeing a patient who presented with confusion and had symptoms which were vague who turned out to have GCA.' More recently a patient was referred to her who had gone to A&E with some sight loss in one eye but with no headache and was thought to have had a stroke. Dr Price diagnosed GCA. 'I realised what it was likely to be when she told me she had had jaw pain when eating and weight loss.' Once on the right treatment the patient recovered.'

Dr Price is very sympathetic about

the difficulties caused by steroids and knows too that it can be very difficult to come off them. 'I think things will change in the future with the wider availability of other drugs.' She notes that Tocilizumab is now available for some patients in limited circumstances. This follows the lobbying of NICE by PMRGCAuk and Dr Price says that patient groups like ours are very important in lobbying both NICE and government to ensure the patient voice is heard.

The guidelines for diagnosis and treatment for PMR are currently being reviewed so they can be updated. New guidelines for GCA have been awaited for some time. They give guidance to doctors as to how to diagnose GCA, the need for speedy treatment and drug treatment. Dr Price says that BSR, which has key responsibility for the introduction of the guidelines in the UK, hopes they will be issued early next year. We will keep members updated on progress.

We would like to thank Dr Price for her time in giving us this interview.

FUNDRAISING & AWARENESS



"I would never have got through the last two years without you. Thank you with all my heart."

10TH ANNIVERSARY £50,000 APPEAL UNDERWAY

With an estimated 50,000 people diagnosed with PMR in the UK each year and a further 12,000 with GCA, we are pushing forward with our drive to raise funds to support even more people. Our total so far is nearing £6,000, thanks to the generous support of members and friends.

The £50,000 target, to mark our 10th Anniversary, will help us to introduce new services and support, including:

Growing our national network of Support Groups

Support Groups around the UK help those with PMR or GCA to feel less isolated, to come together & share experiences and often hear from speakers about the best coping strategies and the latest research into new treatments. We urgently need more groups to ensure everyone has this vital support opportunity.

Developing a new buddy support system

The symptoms of PMR and GCA can prevent some people from accessing group support meetings. We plan to offer a 'buddy' programme with more regular 1:1 support for those who are more isolated and anxious.

Campaigning to raise vital awareness

Lack of awareness of PMR and GCA – whether it's the medical profession, employers or the public – can cause real problems. There can be a risk of incorrect diagnosis or a delay, loss of work and feelings of isolation. We want to step up our campaign activity to raise greater awareness online, in the media and by reaching out to the medical profession.

We have already achieved so much in 10 years. Awareness has increased and more people with PMR and GCA are getting the support and information they need. But there is still so much more to be done.

CAN YOU HELP?

We need the help of all our members and supporters to reach our target of £50,000. Can you help by making a donation or running an event?

If you can, please send a cheque payable to PMRGCAuk to BM PMRGCAuk, London WC1N 3XX or donate securely online at <https://uk.virginmoneygiving.com/fund/PMRGCAukappeal>

If you are organising a fundraising event for the 10th Anniversary and would like it featured in NewsWire please contact liora@pmrgca.org.uk



RAISING AWARENESS IN GP SURGERIES

Janice Maddock, trustee of PMRGCAuk, has always taken a keen interest in raising awareness and told us about her recent success at Wood Lane Medical Centre. 'I was delighted to be asked by my GP surgery to be involved in health promotion for PMR & GCA. I was approached by the Deputy Practice Manager – I had already been putting leaflets in the surgery (with permission) and, once realising I was the 'leaflet fairy', she asked for my input which was fantastic news.'

Having met and agreed a plan, they felt PMRGCAuk week in June would be an ideal time to raise awareness – including displays in the waiting area of the surgery, information on the website and a talk to nine receptionists and the Practice Manager about the general signs and symptoms of PMR & GCA as well as information about the charity.

'There were lots of questions and interest and the feedback after was very positive. Two GPs from the surgery have since taken up our Professional Membership. I hope this will be the start of an ongoing dialogue. A possible 'Meet Up' may be set up if there is enough interest and I know I will be able to advertise it there.'

The Deputy Practice Manager, Cliona, commented "It felt really special to promote PMR & GCA. It was excellent having Janice's support and her enthusiasm for raising awareness and educating the public is infectious!"

Like to do this at your local GP or Health Centre? Contact Janice Maddock on janice@pmrgca.org.uk.



Share
your
Story!

Are you able to share your story to help other people with PMR or GCA?

To raise awareness and fundraise, it helps if people understand the conditions through real stories. If you want to share your journey with us and the importance of PMRGCAuk to you, please contact liora@pmrgca.org.uk

ULTRASOUND AND GCA A PERSONAL EXPERIENCE

Keith Slater, trustee and treasurer for PMRGCAuk shared his experience with us.

'Like all those of us with GCA its diagnosis came as both a real shock followed by the relief that it had been identified before I had lost any of my sight due to it.

My first visit to the Nuffield Orthopedic Centre in Oxford and the long discussion with a rheumatologist about my symptoms and blood counts confirmed that they were a classic manifestation of PMR and GCA. I expected that to lead to a dreaded biopsy which I wasn't looking forward to. "Right" she said, "Let's get it checked out." To my surprise we just went to the room next door and I had my first introduction to the scanner! To me it was a fascinating process and I must have driven them mad with my endless questions about what they were doing, what they were looking for and what they had found. Basically the scan allows them to look at a long cross section of the appropriate arteries to see if there

are any halos present which indicate the inflammation that comes from GCA. Early use of the technique is very important because the size of the halo diminishes measurably after a number of days of glucocorticoid (Pred. to you and me) treatment. And there was evidence in the temporal arteries on the side of my head and also in the axillary arteries under both arms. That was the start of a long friendship with the scanner.'

'My next scan came far quicker than I had expected when I was called two days later to go back in again. It turned out the hospital was running an international scanning course and they needed a guinea pig. So I was scanned 8 times by doctors and technicians from places as wide apart as the Philippines, China and Italy. Thankfully they all came up with the same diagnosis!'

'I've had scans on many of my visits since then with the worst result coming just a year ago when I had a

large flare up (combined with Bell's Palsy) but the halos were only in the right temple. Scans revealed the same again in March and Leflunomide was added to my pill cocktail but my latest scan in May showed the arteries were all clear. Remission? Who knows. But putting my return out to six months instead of three is really encouraging.

Last week I attended Professor Dasgupta's Masterclass on the role of scanning in GCA diagnosis with a large audience getting the opportunity for some hands on practice. The more medical people we can get to be qualified scanners and the more scanning installations we can get in the NHS then the more significant improvements there are going to be in the diagnosis and monitoring of GCA. Perhaps that monitoring will become so regular that the Pred. reduction can become better controlled and the incidence of flares significantly reduced.'



Your feedback on Members' Day

Thank you for giving us vital feedback which will help us to make 2019 even better.

Some of the things you liked:

- The chance to interact with people with the same condition
- High quality speakers and the opportunity to learn more
- Research updates
- The organisation of the day
- Hearing about the success of PMRGCAuk
- Socialising & meeting friends
- Value for money

Things to consider for next time:

- More breaks
- More time for speakers Q&A
- Less medical jargon
- Supporting those who come alone

ARTHRITIS CHARITIES JOIN FORCES

We caught up with the team from Versus Arthritis after their merger earlier this year. 'Arthritis affects millions of people in the UK every single day, taking away their independence, and is one of the major health issues in the UK today. Yet for large numbers of the public, arthritis is seen as inevitable, untreatable and "just a bit of pain". This climate of tolerance is unacceptable and as Versus Arthritis, we want to put an end to it.'

'We know that there is much to be done to improve the lives of millions of people with arthritis, and we cannot do this alone. We're looking to other organisations like PMRGCAuk to understand how our visions align and where we can work together.'

PMRGCA: A SURVIVAL GUIDE

Since its publication this book has quickly become a bestseller. Kate Gilbert, PhD. distilled what she learned from having PMR (and recovering!), and from years of working alongside other sufferers, rheumatologists and researchers, as a trustee of PMRGCAuk. Kate says "I have tried to write the book that I would have liked to read when I had PMR, not only when I was first diagnosed, but also a few months in, when I realised that it wasn't going to be as straightforward as they had led me to believe."

It is now available for Kindle and in paperback from Amazon <http://bit.ly/pmrbk2ed> Price for the paperback is £10.03 plus p&p. If you are unable to order the book from Amazon, write to polywotsit@gmail.com to order via PMRGCAuk.

Join our PMRGCAuk community and make your experience count

PMRGCAUK
HealthUnlocked

Get help to manage your health and lifestyle from others with polymyalgia rheumatica and giant cell arteritis and from the charity, PMRGCAuk.

It's free, easy to use and it's just waiting for you!

The online community gives you:

- Answers to your health questions from other patients
- Support from other PMR and GCA sufferers
- Ideas for treatment and lifestyle choices that could help
- Health issues and debates relevant to you



Take control of your health and join today

pmrgcauk.healthunlocked.com

CHRISTMAS CARDS

Thank you to everyone who bought cards and commented on the wonderful designs again this year. By sending PMRGCAuk Christmas cards you are spreading the word about the support we can offer to everyone affected by PMR and GCA.





SUPPORT GROUP AND MEET UP CONTACTS

Our network of groups around the country is growing! Scotland and the North East are independent organisations. If you don't have a group near you and would like to help us start one, please contact groups@pmrgca.org.uk or 0300 999 5090.

NORTHERN IRELAND

LISBURN MEET UP

Contact: Caroline Stewart
pmrgca.ireland@gmail.com

SCOTLAND

PMR-GCA SCOTLAND

Contact: Lorna Neill (Chair)
www.pmrangca.org.uk
info.scotland@pmrangca.org.uk
Tel: 0300 777 5090

WALES

CARDIFF SUPPORT GROUP

Contact: Sue
cardiff@pmrgca.org.uk

NORTH WEST ENGLAND

ILKLEY MEET UP

Contact: Sue
ilkley@pmrgca.org.uk

KENDAL, CUMBRIA MEET UP

Contact: Win Sayers
groups@pmrgca.org.uk
Tel: 01539 535859

MIDLANDS ENGLAND

COVENTRY MEET UP

Contact: Ann Hollingsworth
pmrgca.coventry@gmail.com

EAST MIDLANDS SUPPORT GROUP

Contact: Bridget
eastmidlands@pmrgca.org.uk

SHROPSHIRE MEET UP

Contact: Joan
shropshire@pmrgca.org.uk

EASTERN ENGLAND

BEDFORDSHIRE MEET UP

Contact: Lyn/Karen
bedfordshire@pmrgca.org.uk

CAMBRIDGE MEET UP

Contact: Trisha
cambridge@pmrgca.org.uk

EAST ANGLIA SUPPORT GROUP

Contact: Dr David Rose
pmrgcaeachair@btinternet.com

HARLOW MEET UP

Contact: Julie/Jean
harlow@pmrgca.org.uk

SOUTHEND/CHELMSFORD SUPPORT GROUP

Contact: Pat Fedi
southend@pmrgca.org.uk

WOODBIDGE MEET UP

Contact: Susan
groups@pmrgca.org.uk

SOUTH WEST ENGLAND

BATH MEET UP

Contact: Pat Martin
pmrgca.bath@gmail.com

BRISTOL GROUP

Contact: Bridget/Felicity
bristol@pmrgca.org.uk

CAMBORNE MEET UP

Contact: Margaret
camborne@pmrgca.org.uk

CHRISTCHURCH MEET UP

Contact: Deidre Harding
pmrgca.christchurch@gmail.com

PLYMOUTH SUPPORT GROUP

Contact: Geoff
plymouth@pmrgca.org.uk

PORTISHEAD MEET UP

Contact Judith
portishead@pmrgca.org.uk

SALISBURY MEET UP

Contact: Patrick O'Donnell
pmrgca.salisbury@gmail.com

SOUTH WEST (TAUNTON) SUPPORT GROUP

Contact: Wendy Morrison
pmrgca.southwest@yahoo.co.uk

TORBAY MEET UP

Contact: Trish
pmrgca.torbay@gmail.com

GREATER LONDON, ENGLAND

GREATER LONDON SUPPORT GROUP

Contact: Anne
londonpmrgcauk@gmail.com

BARNET MEET UP

Contact: Derek
barnet@pmrgca.org.uk

HARROW/PINNER MEET UP

Contact: Jennifer
pinner@pmrgca.org.uk

HIGH WYCOMBE MEET UP

Contact: Alison
pmrgca.highwycombe@gmail.com

ORPINGTON SUPPORT GROUP

Contact: Penny
pmrgca.orpington@gmail.com

SOUTH AND SOUTH EAST ENGLAND

BRIGHTON MEET UP

Contact: Catherine Spencer
brighton@pmrgca.org.uk

CHICHESTER MEET UP

Contact: Patricia Dawson
chichester@pmrgca.org.uk

HASTINGS MEET UP

Contact: Penny
pmrgca.hastings@gmail.com

MAIDSTONE SUPPORT GROUP

Contact: Margaret Hicks
pmrgca.maidstone@gmail.com

OXTED MEET UP

Contact: Debbie Pitt
pmrgca.oxted@gmail.com

PORT SOLENT MEET UP

Contact: Valerie Bidewell
pmrgca.portsolent@gmail.com

SEVENOAKS MEET UP

Contact: Penny
pmrgca.sevenoaks@gmail.com

SURREY SUPPORT GROUP

Contact: Shirley O'Connell
pmrgca.surrey@btinternet.com

WORTHING SUPPORT GROUP

Contact: Christine/Catie
worthing@pmrgca.org.uk

If no telephone number is listed for your group, please call the office on 0300 999 5090.