



PMRGCAuk launches Rheuma Research Roadshow

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 **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.

PMRGCAuk members are always keen to learn about what research is going on into Polymyalgia Rheumatica and Giant Cell Arteritis. We also agree that there isn't nearly enough of it!

It can be hard sometimes to make sense of the world of medical research, and really understand the implications of new research findings.

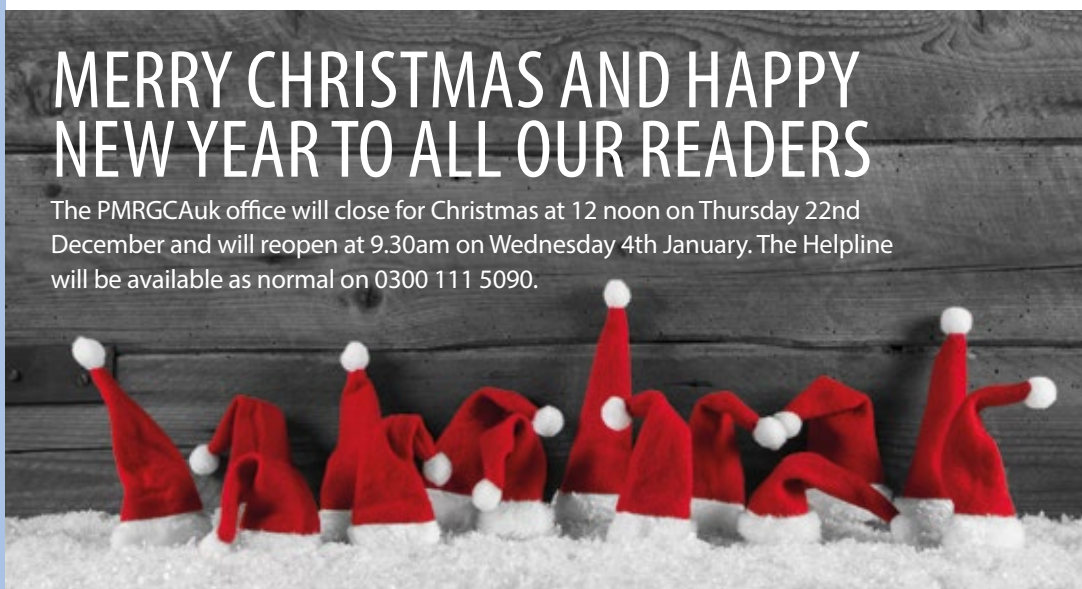
That's why we're excited to announce that we have secured funding from the world-renowned Wellcome Trust for a series of 'Research Roadshows'. During 2017, the PMRGCAuk project group will be teaming up with support groups,

meet-up groups, top rheumatology departments and universities, to hold half-day workshops all around England and Wales. These workshops will provide a chance to learn more about current and future research, raise awareness about new perspectives on these conditions, and give researchers and patients the chance to put their heads together informally to share ideas and experiences. Along the way we will be collecting material to form the core of a free online course to be offered in 2018.

Altogether there will be 12 Roadshow workshops, hopefully one in every region. Every group and every member will have the chance to be involved in this exciting venture and we'll be keeping you up to date with developments in future issues and on the website. If you would like more information at this stage, or would be interested in hosting a workshop, please contact Kate on kate.gilbert@pmrgca.org.uk

MERRY CHRISTMAS AND HAPPY NEW YEAR TO ALL OUR READERS

The PMRGCAuk office will close for Christmas at 12 noon on Thursday 22nd December and will reopen at 9.30am on Wednesday 4th January. The Helpline will be available as normal on 0300 111 5090.





Survey of UK Physiotherapists IN PMR (aka the “SPIN PMR” study) – Keele University

Readers may be aware that researchers at the Research Institute for Primary Care and Health Sciences at Keele University in Staffordshire are undertaking several studies relating to Polymyalgia Rheumatica (PMR). As the Principal Investigator for one of these studies, I am pleased to update you about our first study relating to physiotherapy in PMR – one of the first ever, to our knowledge.

Having worked for over 15 years as a clinical rheumatology physiotherapist, I have always felt that physios have an important role working with people with PMR, but there is very little research to inform our clinical practice. Now in an academic role (lecturing and researching), I want to seize the opportunity to do something about this. So I started this work in September 2015 as part of my PhD studies under the guidance of Professor Christian Mallen.

Readers will be very aware that PMR is an inflammatory musculoskeletal disorder which is relatively common, even if not heard about frequently. We know that physiotherapy interventions are recommended by international guidelines – particularly relating to exercise therapies – and indeed you may yourself have felt the benefit from exercising, but some patients may be concerned that they will make their symptoms worse. So we designed our research study to help start answering some important questions about the role of physiotherapy for people with PMR.

The “SPIN PMR” study aims to start by describing UK-based physiotherapists’ clinical practice with PMR patients. Having got ethical approval from the University Ethics committee, I sent out (with a lot of help from colleagues) a 15 page survey questionnaire to just over 4,000 UK physiotherapists, all working with people with musculoskeletal conditions.

The questions I asked focused around five main areas:

1. Some details about my “respondents” e.g. their gender, age, how long they have been qualified and where they mostly worked e.g. in a hospital, in primary care or private practice, in industry, in a university or other setting.
2. How much training they had previously received relating to PMR, via their undergraduate degrees or from courses or conferences.
3. What they typically include in their physiotherapy assessment for people with PMR and how long they take to assess their patients.
4. What treatment techniques they find beneficial in PMR, including exercise therapy and self-management advice.
5. How do they measure with their patients if their physiotherapy treatments are being effective?

I am pleased to report that 1,056 physiotherapists participated in the 73-item survey questionnaire; this was a response rate of 24.6% which is fairly typical for these types of studies.

Where do we go from here?

This survey is the first known study of contemporary physiotherapy practice with PMR patients, but not the last. There is much more work to be done. I am continuing to analyse the survey data and will follow this up by interviewing some of our respondents to get more insight into their experiences of working with PMR patients. We will continue to work to generate best practice physiotherapy evidence to support international

clinical guidelines. I am also hoping to tell the wider physiotherapy community about some initial results from the survey at the World Congress of Physiotherapy next summer in Cape Town, South Africa, and hope to ignite more interest with other overseas colleagues to research more about specific treatments which can be used in PMR. I will keep you posted!

Anne O’Brien – M Phil, MCSP, Senior Lecturer and NIHR Clinical Doctoral Research Fellow, Keele University.



By the time you read this edition of NewsWire about 5,000 people will be receiving a Christmas card from a friend who is also a member or supporter of PMRGCAuk.

As well as a seasonal greeting, every card carries the message: PMRGCAuk offers information and support to all affected by the debilitating conditions of polymyalgia rheumatica and giant cell arteritis; the charity also provides information, helpline, newsletters, forum, website, support groups and meet ups round the country.

We’ve learned a lot too! We have had to return to the printer three times because we’ve sold out. We now know that very many of you love robins – and we added a nativity card by popular demand. Thank you so much to everyone for their part in spreading our message and helping to make our first Christmas card venture a great success. Happy Christmas to you all!



Christine Catterall with her support crew Matthew Davenport (L) and Matthew Catterall (R)

CHRISTINE CATTERALL'S CYCLE CHALLENGE

Congratulations and a huge thank you to Christine Catterall, who raised £501 for PMRGCAuk with her 21 mile sponsored bike ride on 28th August.

We can only continue our work because of the support and generosity of people like Christine. If you could help with fundraising (a sponsored event, coffee morning, bring and buy sale, raffle or something completely different) please do get in touch with kathryn@pmrgca.org.uk and we will give you all our support! Thank you.

This is Christine's story:

"In 2014, I was diagnosed with PMR and was devastated to find that I was no longer able to do all the things that I used to be able to do. The daily dose of steroids helped enormously, but in turn they have some serious side effects. I tried in vain to reduce them to a lower level but experienced very painful flare ups. I am now taking an alternative medication (methotrexate) and have felt much improved since. As a personal challenge, I wanted to raise awareness and money for PMRGCAuk, in the form of a cycle ride around the Preston Guild Wheel. For many this is a walk in the park, but for me it was major!"

We are so grateful to Christine for raising money and awareness for the charity. If you would like to sponsor her it's not too late – please visit: <http://uk.virginmoneygiving.com/ChristineCatterall>

LETTER TO THE EDITOR

Ten years ago, at 55 years old, I started to have severe pains in all my joints.

My local doctor suggested it was old age and told me to take Ibuprofen tablets. I tried for almost a year, as each time I tried broaching the subject I was given the same answer by my GP. Out of desperation I paid privately for a second opinion at Springfield Hospital's GP practice. That doctor took one look at me, did some simple exercises and diagnosed PMR. He said he would confirm it with blood tests – which turned out positive. A high dose of steroids almost overnight took the pain away.

Over the years I have had flare ups and have again been prescribed steroids, although it soon settles down. But one other problem I did encounter – and the main reason for contacting you is to make fellow patients aware.

About a year ago, I began to get increasing pains in my shoulders and despite high doses of steroids (60mg per day as prescribed by my doctor) I was still suffering severe pain. At a loss as to what was causing the problem, my doctor referred me to a specialist at Broomfield Hospital.

To cut a long story short, following numerous x-rays, ultrasound scans and general prodding about, I was finally diagnosed with rotator cuff tears in both shoulders. I eventually had keyhole surgery to repair my shoulders, and you will be pleased to hear that I am completely pain free and off steroids.

So I would suggest that if my fellow members suffer severe pain that cannot be relieved by high doses of steroids, make a nuisance at your doctor's and insist on a second opinion, as PMR may not be the only cause.

Robert Adams, Maldon, Essex



Photograph: © Robert Lawrie

WELCOME CLAIRE JONES, OUTREACH COORDINATOR

I have recently been appointed as Outreach Coordinator which is a new post in the organisation. Its primary purpose is to support and develop the growing network of support groups and meet-ups. I am delighted to be part of PMRGCAuk, as I am passionate about the value of peer support, having found it a lifeline when I was diagnosed with an autoimmune disease in my 20s.

After university I worked for the NHS with people with learning disabilities and challenging behaviours. I then went on to work for national health related charities by setting up user groups, providing support to small charities and researching patients' perspectives and concerns. For the last 12 years I have managed patient public

involvement organisations, which helped monitor and review NHS delivery from a patient's perspective.

For the past nine years I have lived in Brighton with my husband and our two small children. My interests include craft, cooking and vintage toys.

My main duties for PMRGCAuk will be to co-ordinate and support our network of support groups and meet-ups, to produce resources to help group organisers and co-ordinate the recruitment, induction and retention of group volunteers.

I am looking forward very much to working for PMRGCAuk and helping those affected by Polymyalgia Rheumatica and Giant Cell Arteritis.

Claire Jones



HealthUnlocked



Join our PMRGCAuk community and make your experience count

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



NEWS FROM SURREY

At their latest meeting, the Surrey group was treated to a visit by one of their favourite guest speakers and mentor to the group, Consultant Rheumatologist, Dr Rod Hughes, from St Peter's Hospital, Chertsey. Dr Hughes gave a very interesting and informative slide show presentation and talk on the long term effects of PMR and treatment. Sixty-two members, including relatives and partners, turned out to hear this popular speaker – their largest attendance to date.



ACROSS THE COUNTRY



SOUTH WEST SUPPORT – 3 MEETINGS IN 3 DAYS

August 1st in Bath... August 2nd in Taunton... August 3rd in Plymouth

I have been leading the support group in Taunton for many years now and over those years I like to think that we have been able to inform, support and even have a laugh with probably now hundreds of people, and improve their quality of life. However, it has been such a shame that many people who have expressed a wish to join us have been unable to cope with the journey to Taunton while feeling poorly.

So for me it is wonderful that people are now volunteering to run Meet Up groups, making the support we provide available to many more. To all our volunteers, I would like to say an enormous THANK YOU. I am sure you do not realise just how important what you do is and how much it matters to others, you are all making a huge difference.

This year in the South West, we have monthly meetings in Bath and Taunton and we are currently in the process of planning 3 or 4 speaker meetings in Taunton for next year. In addition, we have regular meetings in Plymouth, Torbay and Salisbury. So we now have 5 groups in our area and I can only say WOW! Where will be next... Bristol? Cardiff?

Sadly we had to say thank you and goodbye to Sally on August 3rd as her own health is of course more important. Despite health issues, Sally and Derek are still raising awareness and fundraising for us – good luck with the operation in November. This means we are now looking for someone to help run the group in Plymouth. If you would like to help in Plymouth (or anywhere else in the South West) please contact me at pmrgca. southwest@yahoo.co.uk or via the national office line 0300 999 5090. **Wendy Morrison**



GUEST SPEAKER HELPS GET LONDON MOVING

The London support group has been fortunate in welcoming a range of excellent speakers at our quarterly meetings at the Artizan Street Library.

Our October meeting was no exception, when we were joined by physiotherapist Liam Rodgers from Ten Health and Fitness. He gave an inspiring talk about the importance of keeping moving and explained that a physiotherapist can help each of us to find suitable exercises.

Liam discussed some of the side effects of steroids – osteoporosis, increased abdominal fat deposits, slower wound healing and depression – and ways in which physiotherapy can help address them, as well as providing us with some top motivational tips.

Ten are kindly offering a first Physio-Led Pilates class for free (normal cost £35 per class) to any PMRGCAuk members who book in for an initial consultation. Find out more here: https://www.ten.co.uk/services/pilates/class-physio-led_pilates



Bath meet up



Sevenoaks meet up



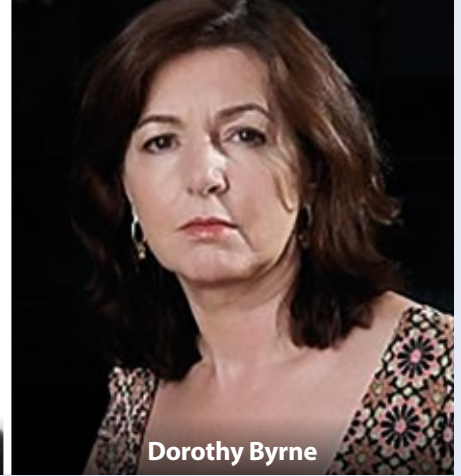
Taunton meet up



Chris Young



Lady Wendy Levene



Dorothy Byrne

TAKE THREE...TRUSTEES

There are currently seven PMRGCAuk trustees supported by three part-time members of staff and numerous volunteers. We are a small charity aiming to support anyone in the UK who has PMR or GCA. To make this happen our trustees have to be 'hands on'. We asked three PMRGCAuk trustees about the part they play in the running of the charity.

Dorothy Byrne is the Head of News and Current Affairs at Channel 4 Television and Chair of the international Ethical Journalism Network. **Chris Young** is a recently retired Paediatric Physiotherapist who has worked in a number of children's hospitals including Great Ormond Street. **Lady Wendy Levene** is a former Lady Mayoress of London and trustee of the Jewish Museum in London where she helped to raise £10 million for extension and renovation work. For their full biographies please visit www.pmrzca.co.uk/content/who-we-are

When did you become a trustee of PMRGCAuk?

Dorothy: Soon after diagnosis of my PMR and GCA.

Chris: I think it was three years ago. I can't remember exactly!

Wendy: I became a trustee in 2008.

Why did you volunteer to be a trustee?

Dorothy: Because there is such a great need to improve diagnosis and treatment of the conditions and to support people with the conditions.

Chris: I didn't actively volunteer! The suggestion was made to me and I

agreed to my name going forward at the next AGM. I am excited to be part of a relatively "new" charity and to see it grow so quickly.

Wendy: Kate Gilbert approached me, after I appeared in an article in the Daily Mail on the condition, and asked me if I would like to become a trustee.

What is your role in PMRGCAuk?

Dorothy: I help with publicity and with lobbying and informing government officials and politicians.

Chris: I run and co-ordinate the Helpline and support the volunteers who participate on it. I also co-run a local support group on the South Coast.

Wendy: I am involved in fundraising and have organised a number of successful events.

What do you enjoy most/find satisfying about being a trustee?

Dorothy: It's wonderful to welcome people to their first ever group meeting at which they meet other people with the conditions and feel much less lonely.

Chris: Achieving the goals we set for the charity to help support people with PMR & GCA, knowing that we

have made a difference to those who contact us in various ways and I enjoy being part of a great team who are all lovely people and fun to be with.

Wendy: To see the profile of PMRGCAuk improve so many people's lives, with a wonderful group of volunteers who work so tirelessly to help sufferers of the condition. In my very small way with raising money I have seen this grow over the last few years.

How do you measure the success of the charity so far?

Dorothy: We are a genuinely influential voice in the fight to improve diagnosis and treatment and we are reaching more and more people with the conditions every month.

Chris: From the positive feedback of many folk who have found the information and help given by the charity invaluable.

Wendy: Thanks to a diverse collection of trustees who all contribute in some way to the organisation and having permanent part-time paid staff who without doubt have raised the profile and efficiency of the charity. We hope to go from strength to strength with our excellent leadership.



MESSAGE IN A BOTTLE WHAT A GREAT IDEA

Patrick O'Donnell, Salisbury meet-up facilitator, tells us of a visit to the group by Gilbert, a member of the local Lions Club in Salisbury. Gilbert gave members some information that could help us all.



Patrick O'Donnell,
Salisbury meet-up facilitator

Lions* Message in a Bottle is a simple, but effective, way to keep essential personal and medical details where they can be found in an emergency – the fridge.

More than 5 million FREE Message in a Bottle kits have been distributed by Lions Clubs British Isles & Ireland in recent years to people with conditions such as diabetes, allergies, disabilities and life-threatening illnesses.

The bottles are supplied FREE of charge thanks to generous donations from the public and businesses.

Lions clubs supply the bottles to health centres, doctors' surgeries and chemists. Paramedics, police, fire-fighters and social services support this life-saving initiative and know to look in the fridge when they see the Lions Message in a Bottle stickers.

The Lions Message in a Bottle initiative is praised by hundreds of emergency services personnel. Senior North West Ambulance Service paramedic Steve Nicolls said: "It's of invaluable assistance to us when we have to attend an incident at someone's home."

Talking to Nick Knowles on the BBC's Emergency Rescue programme, Andy Capes, South West Ambulance Service said he can rely on the Lions Message in a Bottle: "I use it on average two or three times a week; it saves time and lives."

TO GET A 'LIONS MESSAGE IN A BOTTLE' KIT

Ask at your GP surgery or local pharmacy or contact Lions Clubs International:

Email: enquiries@lionsclubs.co
Tel: 0845 833 9502

ROOM FOR MORE...

The PMRGCAuk trustees, together with our small and dedicated part-time staff and an increasing number of volunteers, are passionate about helping everyone with the conditions get through the ups and downs of PMR and GCA.

We may not be millennials but we have embraced modern technology keeping our overheads low and keeping in touch straightforward! We work remotely, meeting up whenever we need to, including six times a year

for trustee meetings. Meetings are usually in London but sometimes via video calling such as Skype.

Trustees, staff and volunteers work together to make sure each area of the work we do is supported:

- Awareness
- Campaigning
- Events
- Financial
- Fundraising
- Helpline
- NewsWire
- Administration
- Press & Publicity
- Membership
- Support Groups & Meet Ups

MANY HANDS MAKE LIGHT WORK!

Treasurer

Treasurer Robin Hamilton is looking for someone to take over his role due to other commitments. If you have a background in accounting we would love to speak to you.

Bookkeeper

We would like to find a volunteer bookkeeper to work with the Treasurer.

Trustee with legal expertise

We are seeking a qualified lawyer who is interested in joining us as a trustee.

Support groups and Meet-ups

As we continue to extend the network of groups we are always keen to speak to possible volunteer support group organisers, meet up facilitators and others willing to help. Please contact Claire at groups@pmrgca.org.uk to find out more.

Fundraisers

All fundraising is important to us. Having a few friends in for a PMRGCAuk cuppa and cake or a Christmas drink spreads awareness, and charging a small amount for this raises money to support our work... mighty oaks from little acorns grow! Perhaps you have children or grandchildren who want to run a marathon or do other sponsored fundraising. Please share your ideas with us and we will endeavour to provide you with local publicity and support.

* Lions Clubs in the UK are part of the world's largest service club organisation. Find out more from www.lionsclub.co

Raising Awareness in Hillingdon and Beyond!



I suffer from Polymyalgia Rheumatica (PMR) and I was diagnosed at 55, nearly four years ago. This was after a six-month struggle of not knowing what was wrong with me. Luckily my GP was excellent and picked it up straight away. I had never heard of it but since my diagnosis I have realised that my mum who sadly passed away had it, but had never been diagnosed despite various interventions and care.

Because of this and the constant explaining to friends and family what PMR actually is, I decided I wanted to raise awareness of PMR and GCA with anyone who would listen! I am in the early stages of devising a programme of contacts and visits to raise awareness of PMR and GCA among people over 50 and professionals who work with them.

I have so far spoken to district nurses and community matrons as well as friends and professionals I have come into contact with personally, for example my osteopath, hairdresser and Pilates teacher. I know four doctors' receptionists and they have all displayed notices and leaflets in their surgeries. I have also made a great contact with the London Borough of Hillingdon Well Being Coordinator for Age UK and have attended Well Being groups at three sites of supported housing for older people. This is with a plan to attend more events for Age UK in the future. I have also submitted an application to talk to the Women's Institute (WI).

It has taken a while to get going as I often have to explain about PMR and GCA as well as the statistics to show how common it is, but I now hope to

share this with other people who may want to do something similar in their area by sharing my knowledge and ideas for contacts.

I am in the process of creating templates which will enable people to personalise, record events and contacts in order to measure the impact. I also have the full support of PMRGCAuk who are helping me to coordinate this project.

If you are interested in doing this in your area I am keen to share my experiences and knowledge - please contact me on janice@pmrgca.org.uk

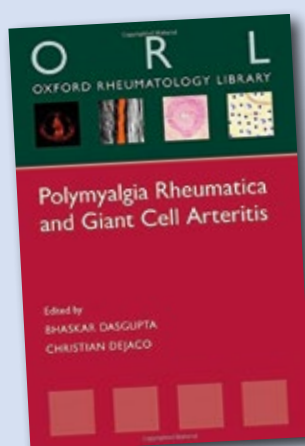
JANICE MADDOCK

BOOKS

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

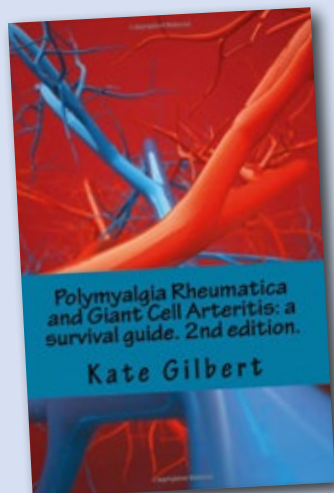
also a few months in, when I realised that it wasn't going to be as straightforward as they had led me to believe."

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.



Part of the Oxford Rheumatology Library series, and edited by Prof Bhaskar Dasgupta and Prof Christian Dejaco, *Polymyalgia Rheumatica and Giant Cell Arteritis* provides quick and practically relevant information on several aspects of the diseases, particularly on diagnosis and management, with the ultimate aim of improving the patient's care. Chapters highlight current

concepts of pathogenesis, recent advances of diagnostic and therapeutic approaches, the ongoing research into the identification of new biomarkers and corticosteroid-sparing medications, and the importance of patient education and support. The book is currently available on Amazon.co.uk for £26.30, or £19.49 on Kindle, or through the Oxford University Press.





NEW GCA GUIDELINES PRESENTATION

As mentioned in the last NewsWire, we were preparing for a mini-conference in Glasgow at the end of September. We chose Greater Glasgow and Clyde (GGC) as the biggest Health Authority in Scotland, looking after 23% of the nation (2010 statistics), with some 2,000 people at risk of developing GCA (statistical extrapolation) where a quick diagnosis is so important.

The published title was 'The diagnosis and treatment of PMR and GCA: New and updated guidelines' hosted by PMR-GCA Scotland and supported by the Scottish Society for Rheumatology (SSR). Our keynote speakers were Professor Dasgupta, who talked about the new GCA guidelines, in particular Fast Track, and Clinical Nurse Specialist, Madeline Whitlock, who presented "The Nursing Perspective". In the chair we were assisted by Dr Anne McEntegart, Honorary Clinical Senior Lecturer (School of Medicine) University of Glasgow. With the invaluable help of Dr Elizabeth Murphy, Consultant Rheumatologist and current chair of the SSR, we were able to secure 3 category 1 (external) CPD credits (approved by the Federation of the Royal Colleges of Physicians of the United Kingdom) for attending participants. I cannot believe that we were starting to plan this at the end of 2015 and now it has happened!

We had bookings from over 70 medical professionals including GPs, practice nurses, consultants and other disciplines as well as eight of our members, a trustee from the North East of England and three Scotland trustees. Unfortunately, as you would expect with such a front line mix, there were people who couldn't make it through on the day, but the feedback (formal evaluation) was encouraging.

There were a few negatives, probably the most significant being 'not enough time for Q&A' (regrettably Professor Dasgupta was tied to a return flight). I do want to share some encouraging comments that participants made when asked what impact this event would have on their future practice 'Development of fast track GCA service' (**Hoorah!**); 'More aware of how patient feels' (**Great!**) and 'Recognise the role of patient organisations in the support and care of patients' (**Brilliant!**). At least one practice is planning to adopt Madeline's first interview technique and a copy of her interview sheet will be made available throughout the GGC networks. Delightfully, and despite previous mailings, we have been asked to supply sufficient information leaflets so that each of the 200+ GP practices in the Greater Glasgow area has 10 readily available. With an average of five GPs in each practice, no GP should remain unaware of us.

The event was intended for medical professionals, and much of the information was very technical, but I thought it would be helpful to understand how our people felt. Bamboozled, depressed, excited? A bit of all I think. This was what one member said:

"...both presentations were very clear and informative even to a non-medical attendee, although I did have to look up some terms after the event for confirmation. It was a real privilege to listen to someone as eminent as Professor Bhaskar Dasgupta. His presentation was clear and to the point. Madeline Whitlock captured the patient perspective perfectly, matching my experience, apart from the initial fear of steroid side effects, the latter being due to my previous total ignorance of the subject."

OTHER NEWS

After four years at the helm, I have decided that it is time for me to step down from the charity. Looking back at the time since Jean Miller retired, I feel that we have managed to build on her amazing work and the charity is now firmly established in Scotland. There is still much to do but the mechanisms are slowly clicking into place. The charity's secretary, Lorna Neill, has now stepped into the role of Chair while Michael Benneworth, who looks after the database and mailing of information packs and so on, has taken on the secretarial position. Our invaluable treasurer, Harvie Findlay, continues to keep a tight rein on the spending, which means that the trustees need to be able to justify any large expense before it happens. No bad thing!

With my very best wishes to you all



Bea Nicholson



HELPLINE

0300 777 5090

www.pmrandgca.org.uk

Registered Scottish Charity No
SC037780

Registered address
Forest Lodge, Foulden,
Berwickshire TD15 1UH



Q&A WITH PROFESSOR DASGUPTA

Our President, Professor Bhaskar Dasgupta, very kindly agreed to answer some of the questions raised by members at the summer London support group meeting. We thought everyone would like to benefit from his very helpful responses.

What long-term effects do steroids have on the liver and other organs?

No effect on the liver. Steroids can affect weight and muscle and cause diabetes, hypertension, glaucoma, hardening of the arteries, psychological problems and depression

Am I tired because of the illness, because of the steroids or both?

Both, as well as the psychological effect of long-term illness.

Should I take calcium or not, alongside vitamin D?

Yes, either in your diet or as tablets. In the diet is better.

What are the relative benefits of taking alendronic acid by mouth and zoledronate infusions? I have heard taking it by mouth increases the risk of cancer of the oesophagus

Alendronate is much cheaper and easier to arrange. The risk of oesophageal cancer is over-reported. We have to consider resource utilisation as well.

Is magnesium useful?

No, unless there is a diarrhoea illness.

Does turmeric really make any difference?

Don't know - it's been used for years as part of staple food in India.

When during the day should I take my medication?

Morning, after breakfasts.

Are probiotics useful to help with digesting the tablets?

Not needed unless there is diarrhoea or malabsorption.

Do steroids increase perspiration

They shouldn't except for the fact that weaker muscles mean you may have to struggle harder.



Do steroids cause palpitations?

As above, except at very high doses which can cause circulatory effects.

Do steroids affect bowel movements?

They should not do so.

Do steroids cause weight gain and how much?

Yes. A lot depends on the steroid dose.

Would aromatherapy or other alternative therapies work?

I don't know.

Can steroids cause jaw disintegration and/or make teeth fall out?

Osteoporosis in that area is definitely a problem we have to be aware of. Medications for bone protection can cause this problem rarely too if given for more than 10 years.

What is a flare-up and what should I do when I get one?

An increase in the morning pain and morning stiffness. Usually caused by the rise of inflammatory markers. Consult your doctor.

Are flare-ups related to stress?

They can be as the body and mind are connected.

It would be really helpful if there was a half mg prednisolone tablet.

I agree.

The 1mg and 5mg tablets look too similar. How could we contact drug companies making that point?

Write to the ABPI regulator of the pharmaceutical industry. (NB. PMRGCAuk have done so.)

What's the difference between a coated and uncoated tablet?

Uncoated tablets are much cheaper and better and more reliably absorbed. We do not have coated tablets in our pharmacy or formulary.

Are people with PMR warned they can get GCA? What percentage of those with PMR get GCA?

They are warned but we should also not alarm them too much. The percentage of people with PMR who get GCA is 10-15%.

Do PMR and GCA come on quickly or is it just that we suddenly become aware of them?

The onset of both PMR and GCA tends to be abrupt - we use the fact of acute onset to differentiate from other mimicking illnesses.

Is it genetic? What causes it?

It's not genetic but is more common in first degree relatives.



Photographs: © Robert Lawrie

“Life with Five Prime Ministers”

Oh what a treat. Wednesday 19th October was a very special day for PMRGCAuk as our 100+ guests sat down in the Cholmondeley Room and Terrace to enjoy a delicious afternoon tea of sandwiches, scones and cakes in the sumptuous surroundings of the House of Lords.

We were privileged to have as guest speaker Lord Robin Butler, who recounted his extraordinary civil service career working closely with Edward Heath, Harold Wilson,

Margaret Thatcher, John Major and Tony Blair. Lord Butler entertained us for almost an hour with warm, funny and moving anecdotes about each of these very different Prime Ministers – and indeed we would have been more than happy to sit, listen and ask questions all evening!

The talk and tea was organised to raise money for PMRGCAuk and in this it was a storming success, raising almost £10,000 – a really significant sum that will make a huge difference to our small charity. This has been a

year of fabulous fundraising events for PMRGCAuk, all arranged by our trustee and fundraiser extraordinaire Lady Wendy Levene. Many of you will have read all about our tours of the Mansion House and Old Bailey, and this was the crowning accomplishment of the year.

We have more events planned for 2017 – to be among the first to hear, please email kathryn@pmrgca.org.uk and ask to join the ‘special events’ mailing list.



Do you work somewhere that could display a PMRGCAuk collecting tin, so that people can donate their loose change? If so, please contact kathryn@pmrgca.org.uk. Thank you!

GETTING THE WORD OUT

If you receive the hardcopy version of NewsWire when you have finished reading it how about offering it to your GP surgery, the local hospital rheumatology department or your local pharmacist.

The more people we tell about the PMR and GCA conditions and how we raise awareness and about the support we offer the better for all!

And if you read the electronic version but want to pass a hardcopy to your GP, rheumatologist or pharmacist we can send to you or we can send direct if you let us have their details.

CHARITY CONTACT DETAILS

Penny Denby, Chair of Trustees
chair@pmrgca.org.uk

Kathryn Busby, Director
Works Mondays, half-day Tuesdays and Fridays
kathryn@pmrgca.org.uk

Claire Jones, Outreach Coordinator
Works Tuesdays and Wednesdays
groups@pmrgca.org.uk

Laurene Brooks, Membership Secretary
Works Mondays
admin@pmrgca.org.uk

Call the office on **0300 999 5090**
Call the helpline on **0300 111 5090**



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 MEET UP

Contact: Caroline Stewart
pmrgca.ireland@gmail.com
Tel: 0300 999 5090

PMR-GCA SCOTLAND

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

MID WALES MEET UP

Contact: Wendy
pmrgca.southwest@yahoo.co.uk
Tel: 0300 999 5090

EASTERN

CAMBRIDGE SUPPORT GROUP

Contact: Dale Hodgson
dalepmrgca@gmail.com
01767 651084

EAST ANGLIA SUPPORT GROUP

Contact: Maryan Fidler
eastanglia-pmrgca@outlook.com
Tel: 01787 379400

PETERBOROUGH SUPPORT GROUP

Contact: Clare Marshall
peterboro@pmrgcauk.com
Tel: 0300 999 5090

SOUTHEND/ESSEX SUPPORT GROUP

Contact: Claire
groups@pmrgca.org.uk
Tel: 07722 827 947

MIDLANDS

COVENTRY MEET UP

Contact: Helene Miles
groups@pmrgca.org.uk
Tel: 0300 999 5090

SHROPSHIRE SUPPORT GROUP

Contact: David Davies
shropshire@pmrgcauk.com
Tel: 0300 999 5090

SOUTH AND SOUTH EAST

CHICHESTER MEET UP

Contact: Robin Hamilton
info@pmrgcauk.com
Tel: 0300 999 5090

ORPINGTON MEET UP

Contact: Penny
pmrgca.orpington@gmail.com
Tel: 0300 999 5090

SEVENOAKS MEET UP

Contact: Penny
pmrgca.seveonaks@gmail.com
Tel: 0300 999 5090

HASTINGS MEET UP

Contact: Brenda Wilson
pmrgca.hastings@gmail.com
Tel: 0300 999 5090

OXTED MEET UP

Contact: Debbie Pitt
pmrgca.oxted@gmail.com
Tel: 0300 999 5090

SURREY SUPPORT GROUP

Contact: Shirley O'Connell
surrey@pmrgcauk.com
Tel: 0300 999 5090

MAIDSTONE MEET UP

Contact: Margaret Hicks
pmrgca.maidstone@gmail.com
Tel: 0300 999 5090

PORT SOLENT MEET UP

Contact: Barbara Winspear
pmrgca.portsolent@gmail.com
Tel: 0300 999 5090

SUSSEX/SOUTH COAST SUPPORT GROUP

Contact: Christine/Catie
pmrgcasouthcoast@btinternet.com
Tel: 0300 999 5090

GREATER LONDON

GREATER LONDON SUPPORT GROUP

Contact: Anne
londonpmrgcauk@gmail.com
Tel: 0300 999 5090

HIGH WYCOMBE MEET UP

Contact: Alison / Sue
pmrgca.highwycombe@gmail.com
Tel: 0300 999 5090

NORTH EAST

PMR & GCA UK NORTH EAST SUPPORT GROUP

Contact: Mavis Smith
www.pmr-gca-northeast.org.uk
Tel: 0191 4111138

SOUTH WEST

BATH MEET UP

Contact: Pat Martin
pmrgca.bath@gmail.com
Tel: 0300 999 5090

SALISBURY MEET UP

Contact: Patrick O'Donnell
pmrgca.salisbury@gmail.com
Tel: 0300 999 5090

CHRISTCHURCH MEET UP

Contact: Sheridan Lake
pmrgca.christchurch@gmail.com
Tel: 0300 999 5090

SOUTH WEST (TAUNTON) SUPPORT GROUP

Contact: Wendy Morrison
pmrgca.southwest@yahoo.co.uk
Tel: 0300 999 5090

PLYMOUTH CORNWALL & SOUTH DEVON SUPPORT GROUP

Contact: Wendy Morrison
pmrgca.southwest@yahoo.co.uk
Tel: 0300 999 5090

TORBAY MEET UP

Contact: Trish
pmrgca.torbay@gmail.com
Tel: 0300 999 5090