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**NATIONAL
HELP LINE**

0300 111 5090

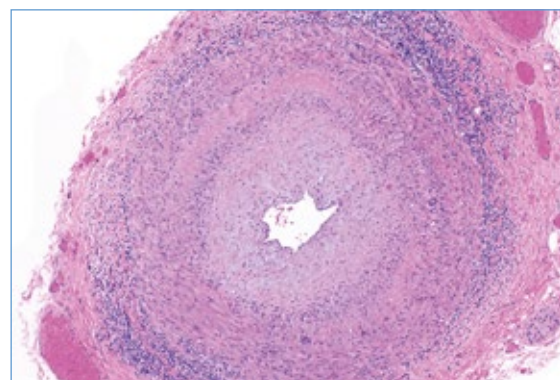
PMRGCAUK is a registered charity established to meet the needs of people with these debilitating conditions by raising awareness, promoting research and offering support.

NICE approves tocilizumab for cases of GCA

In early March, after months of consultation and waiting, we received the news that NICE, the National Institute for Health and Clinical Excellence, has approved the use of tocilizumab for cases of giant cell arteritis.

There has not been a new drug specifically for GCA since steroids were first used 70 years ago.

Tocilizumab (TCZ for short), patented by Roche as 'Actemra', is one of a new generation of 'biologic' drugs that treat the inflammation causing the disease rather than just the symptoms,



A section of an artery affected by large vessel vasculitis

as steroids do. It does this by attaching itself to IL-6, the interleukin chemical that is responsible for much of the inflammation in GCA. The international GiACTA trial has shown that patients taking TCZ can end up taking a much lower overall dose of steroids, avoiding relapses and the dangers of high doses of steroids, such as diabetes and osteoporosis.

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ANNIVERSARY

TENTH ANNIVERSARY APPEAL

WE NEED YOUR HELP

A decade after the meeting that would lead to PMRGCAuk being established, we have launched a fundraising appeal to raise £50,000 in order to transform the service we offer. Please turn to the centre pages to find out more.

In its first report, issued in December, NICE rejected tocilizumab for use in the NHS, despite it having been approved in the USA and Australia. For NICE, the figures didn't stack up, and tocilizumab would be too expensive. One of the issues was that calculations were based on the idea that almost any GCA patient might require the new drug.

The experts and the public were given just four weeks to respond, over Christmas and New Year. PMRGCAuk worked tirelessly over the holiday season to mobilise patients and rheumatology experts. Nineteen patients and a carer registered with NICE so that they could make individual submissions. The British Society for Rheumatology (BSR) also lent their weight with a compelling paper. We would like to say a big thank you to everyone who contributed, especially consultant ophthalmologist Susan Mollan and consultant rheumatologist Justin Mason, who put up impassioned and persuasive arguments for the new treatment in the appraisal meetings.

At the second NICE meeting, it was clear that the efforts of patients and PMRGCAuk had made an impact. There was a consensus emerging that the people who really need this new drug are those who just can't come down from high levels of steroids. But the verdict still seemed touch and go. Roche also offered the NHS a discount in order to help TCZ fit the economic model.

We were delighted to get a broadly positive response from NICE. At the time of writing we are still in an appeal stage, but we believe that people with repeated relapses, or those who don't respond to steroids,

will be able to have TCZ for up to a year on the National Health. By around June, the first patients should start receiving new treatment. Before then, regulations must be worked out and agreed. Only a small proportion of patients, those with 'refractory' disease that doesn't respond to steroids, and people with repeated relapses, will be eligible. And those who are will just get TCZ for a total of one year.

This drug is so expensive to manufacture and administer (via subcutaneous injection), that we and the BSR agree we should not push our luck by appealing the one-year restriction at this stage. Instead, we should go ahead. What would be ideal would be to have a research project to gather as much data as we can while people are on TCZ, to fully measure the benefits. Twelve months may be enough for most people, to allow their bodies to rebalance and counteract the disease.

Comparing GCA with rheumatoid arthritis, we see in RA there are many alternative steroid sparing and disease modifying drugs to try before TCZ as a last resort. In GCA we don't have this second line of treatment. So paradoxically, this approval of a very expensive drug might usher in a new dawn for giant cell arteritis. We hope to see more new treatments developed, as other drug companies see the opportunity. Also, tocilizumab is coming out of patent, and there is a chance that another company might be able to produce a less expensive 'biosimilar' drug that would do the same job, within a few years. GCA, with its pain, its limited treatment options, and danger of blindness, is coming out of the shadows for good.



Dr Sanjay Pathare speaking on ultrasound at the Newcastle roadshow

Research Roadshows project moves into a new phase of development

After the successful programme of research-focused events around the country, the project has collected a small mountain of material from the presentations of the 28 researchers and experts who took part. The next task is to turn it into educational material for clinicians, health and care workers, and patients.

Some of it will work in print form, and we are looking into producing a couple of quick reference 'infographics' that will sum up GCA and PMR for GPs. But we have found that some of it can work as short videos. Where the quality of the original recording allows, we are editing presentations into 5-minute videos that you'll be able to watch on computer, tablet or phone. Right now, you can see giant cells forming before your very eyes, on one of the videos of Dr Gary Reynold's talk at the Newcastle roadshow.

You can find the PMRGCAuk video channel on <https://vimeo.com/channels/pmrgcauk>

As time goes on, we'll be uploading more and more interesting snippets. Meanwhile, we have two more roadshows planned for 2018 – Peterborough on 24 April, and Port Solent on 2 June.



ACROSS THE COUNTRY

NEWS FROM LONDON

On Monday 22nd January, the Greater London Support Group had a visit from Kate Gilbert, project lead for the Rheuma Research Roadshows.

Kate had come to talk to the group about the drug tocilizumab (TCZ) which at the time had not been approved for the treatment of GCA on grounds of cost. (See NICE approves TCZ for cases of GCA, front cover.)

As Kate was due to represent PMRGCAuk at the second NICE appraisal meeting the next day, she was keen to get input from the group to bolster her case for the approval of TCZ for GCA sufferers – particularly for those who suffer from flare ups, as TCZ has the potential to save GCA patients from repeated relapses and

thus their high cumulative dose of prednisolone.

Armed with very useful slides, Kate explained the history of the drug, the NICE approval process and the reason for it not getting approval along with results from a 52-week clinical study of prednisolone v. TCZ.

The group made valid and useful suggestions which Kate took to her meeting with NICE the next day. They aided her efforts to address the cost reasons for not approving this drug for GCA sufferers – with the excellent outcome that NICE changed their decision and approved TCZ for some cases of GCA, as reported in this edition of NewsWire.



NEW PORTISHEAD GROUP ESTABLISHED IN BRISTOL

The photo shows our second support meeting in Portishead.

We were able to use a recently refurbished pub which made us very welcome in comfortable surroundings at no charge, providing we purchased coffee or tea.

Wendy Morrison very kindly came from Taunton to talk about the charity and what members can expect if they join or come to the support meetings. Quite a few leaflets were distributed.

Everyone was interested in the group and several said they were glad there is now help and advice available. Hopefully we can persuade one or two professionals to come along in future and give their advice.

We will continue to meet next year and hope we can offer support to people in our area which has a growing population.

Judith Davies, Portishead Meet Up

VOLUNTEERS NEEDED FOR RESEARCH

The PMRGCAuk team would like to welcome member Jan Sprat who has volunteered to help a new PMRGCAuk research team led by Kate Gilbert. Jan attends the London Support Group and the Oxted Meet Up and keeps up to date with the PMRGCAuk Forum on HealthUnlocked.

The Research Team's primary aims will be:

1. To keep PMRGCAuk members up-to-date with research being carried out by centres of excellence round the UK.
2. To inform members and link them to the many opportunities to participate in research being done in universities and centres of excellence.
3. To be in touch with the consultants and researchers carrying out research and be ready to endorse quality research into all areas of PMR and GCA.

4. To represent the charity at appropriate events.

If you have a little time to spare, access to the internet and email and would like to help, please email kathryn@pmrgca.org.uk. You will receive a full description of the opportunities.

We are keen to find volunteers from all over the UK who would like to work with others passionate to find ways to improve diagnosis and treatment for people with PMR and GCA. As main communication will be by email, it does not matter where you are!



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

Research Round-up

Following on from the successful trial of tocilizumab for GCA reported in the last NewsWire, another study has looked at the potential to use this drug in PMR¹.

The researchers were able to see on scans that those patients that received tocilizumab had improvements in inflammatory signs in the hip and shoulder joints. However, much more work is needed before this treatment could be recommended for PMR. There has also been a small study that suggests that the use of methotrexate in GCA might reduce the risk of relapse (recurrence of symptoms) by up to 72%². Again, we need to know more before changes can be made to guidance on treatment for everyone.

In relation to a study we covered in the last Research Round-up that looked at how long people take steroids for PMR in the United States (on average nearly 6 years), a study using nationally representative data from Germany has shown that the length of treatment in PMR and GCA is longer than the 'textbook' says³. PMR patients in this study were treated on average for between 13 and 18 months before they got down to a dose of 5mg. For GCA, this was 19-24 months.

There have been lots of studies recently looking at different types of scans to better understand PMR and GCA and also how to improve diagnosis. In January, the European League Against Rheumatism (EULAR) published guidance on how to use different types of scans in large vessel vasculitis (including GCA). For GCA, they have recommended the early use of ultrasound and MRI scans to help with diagnosis⁴. Also, related to diagnosis of GCA, a statistical model has been developed to predict which patients undergoing temporal artery biopsy are likely to be diagnosed with GCA⁵. This model is based on the symptoms that a person has and the idea is that those at lowest risk will not need a biopsy. The model still needs some work before it can be used in practice, because we don't want people to be 'missed' and not receive treatment.

Finally, two studies have used big sets of data from UK primary care records. The first compared the rates of death in people with and without GCA⁶. They showed that people with GCA were at an increased risk of dying in the first year after they were diagnosed. This risk decreased over time and was the same as people without GCA after 5 years. Much of this increased risk seemed to be associated with other health conditions that the people with GCA had, compared to people without GCA (e.g. heart disease), although being male and being younger when diagnosed were also associated with

a higher risk. The extra risk of dying in people with GCA was much less in people diagnosed since the turn of the Millennium. The second study looked at the risk of bone fractures in people with PMR and GCA compared to people without these conditions⁷. It found that having PMR gave a 63% increased risk of a fracture, while in GCA this was 67%. Only 13% of people had been prescribed bone protection drugs and the authors (who include me) say more needs to be done to make sure people with PMR and GCA get these treatments. We also need to see if stricter schedules for steroid doses could reduce the rates of fractures.

References

1. Huwart et al Arthritis Research & Therapy. 2018;20:11.
2. Leon et al. Clinical Experimental Rheumatology. 2017 Dec 6. [Epub ahead of print]
3. Albrecht et al Rheumatology International. 2017 Nov 9. doi: 10.1007/s00296-017-3874-3. [Epub ahead of print]
4. Dejaco et al. Annals of the Rheumatic Diseases. 2018 Jan 22. pii: annrheumdis-2017-212649. doi: 10.1136/annrheumdis-2017-212649. [Epub ahead of print]
5. Ing et al. Clinical Ophthalmology. 2017 Nov 22;11:2031-2042. doi: 10.2147/OPH. S151385. eCollection 2017.
6. Lin et al. Arthritis Care & Research. 2018 Feb 6. doi: 10.1002/acr.23538. [Epub ahead of print]
7. Paskins et al. BMC Medicine. 2018;16:4.



Finding the Missing Link

A couple of weeks ago, at choir practice, I was asking one of the altos who is a German translator, if she knew anyone who would be interested in translating my book into German.

"Ooh, have you written a book?" another of the ladies asked.

"Yes" said I. "It's about a disease called polymyalgia rheumatica that I used to have."

Another alto, Ann, broke in.

"Hey, I have PMR. It's no problem though is it? Why would you need a book? You just take the steroids and everything's fine."

Ann is tall and slim, with fine features, and no-one would ever imagine that she is on steroids. She doesn't have hamster face, she doesn't have the "roid rolls", and she's evidently finding it a breeze reducing her prednisolone dose. She would have been the last person in choir I would have guessed had fallen prey to PMR. This really set me thinking.

Why is it that some people with PMR have a relatively easy ride once they are diagnosed and find it uncomplicated to reduce steadily, coming off steroids altogether after a couple of years? My mum was like this, getting off steroids in a year and a half, yet others find it hard to reduce below 10mg, suffer repeated relapses, are never free of pain, and are still on steroids many years down the line.

What if 'simple' PMR and 'complex' PMR were, in fact, different conditions? It would certainly put the cat among the pigeons in rheumatology and it might pose a few questions for our charity. But

would it help to solve a mystery that has been bothering patients and doctors alike, about the links between PMR and GCA?

Around half of people with GCA also complain of 'polymyalgia-like' symptoms, at or before diagnosis. Up to 25% of people with PMR also develop GCA symptoms, and a few unlucky ones even get GCA after being diagnosed with PMR.

Recent years have seen important advances in imaging techniques shedding new light on goings on in the body. Ultrasound scans are now almost as reliable and specific in identifying GCA in the temporal artery as biopsy. A 2014 Danish studyⁱ broke new ground by carrying out ultrasound scans of relapsing PMR patients. Scans were carried out on their temporal, subclavian, axillary and carotidⁱⁱ arteries. Any that had signs of vasculitis (swelling of the arterial wall visible both laterally and longitudinally) underwent a biopsy.

Of the 17 patients in the study, one showed large vessel vasculitis (LVV) in the temporal artery. This patient was the only one to have a positive biopsy. However, another six patients had signs of LVV. All seven showed LVV in the axillary artery, and three showed LVV in the subclavian arteries as well. In all, 41% of the patients in this study showed LVV on the ultrasound scans. The investigators recommended that all patients who relapse while reducing their steroids should have ultrasound scanning for signs of large vessel vasculitis.

Could there even be three forms of PMR? The 'silent' large vessel vasculitis cases that show up on ultrasound scans, the 'simple' ones who have a form of chronic bursitis, perhaps triggered by infection, and the ones in the middle? Would they have something completely different or a less severe manifestation of an autoimmune inflammatory illness?

I would love to see research get to grips with these questions. Perhaps it could be done by carrying out ultrasound and PET scans on newly diagnosed patients to assign them to groups depending on whether or not they show signs of LVV. Close monitoring could be carried out of their steroid dosage patterns, whether they relapse, at what stage, and what symptoms they report. Any supplementary medications and their effects could also be recorded.

Such a study could tell us an awful lot. Not least, those identified as having LVV could then make the case for more sophisticated medications, as are customary now in many different forms of vasculitis. Rheumatologists could learn more about how to manage and prevent relapses, and perhaps those patients who don't have signs of vasculitis could be spared months of taking steroids.

One thing is for sure – we shouldn't stand for doctors telling PMR patients that they have a 'muscle disorder'. The reality is so much more complex than that.

Kate Gilbert is author of Polymyalgia Rheumatica and Giant Cell Arteritis: a survival guide

- i Stavros Chrysidis¹, Philip Rask Lage-Hansen¹ and Andreas P. Diamantopoulos (2014) Polymyalgia Rheumatica Relapse and "Silence" Large Vessel Vasculitis. Is There Any Association? American College of Rheumatology meeting abstracts 2770. <http://acrabstracts.org/abstract/polymyalgia-rheumatica-relapse-and-silence-large-vessel-vasculitis-is-there-any-association/> (accessed 02/02/18)
- ii Temporal artery – in the temple; axillary artery – near the armpit and the first rib; subclavian artery – passing from the aorta towards the neck; carotid artery – in the next feeding the brain.

FUND RAISING

PMRGCAUK
WEEK 18-24 JUNE 2018

YOU'VE GOT TO BE IN IT TO WIN IT... IN OUR GRAND RAFFLE

This year we are holding a raffle with fantastic prizes including a week's stay in a village house on Lake Como, Italy, for up to four people*, a tie donated by Channel 4 News's Jon Snow and a beautiful signed art book by London Group member Frances Treanor. Visit www.pmrzca.co.uk/content/raffle for more prizes as they are announced!

Please email kathryn@pmrgca.org.uk or call 0300 999 5090 to be sent books of raffle tickets (if you received this magazine directly from us there will be a book of raffle tickets enclosed). Sold ticket stubs must be received by 31 August 2018 with a cheque for £1 per ticket payable to PMRGCAuk (or contact us if you'd rather pay the money in online).

The winning tickets will be drawn at our Members' Day on 8th September 2018.

* The week's stay in Italy has been generously donated. A mutually convenient date in 2019 will be arranged with the winner. The prize does not include transport or other costs.

WHY NOT ORGANISE A FUNDRAISING EVENT

Organise a small fundraising activity in your support groups and meet ups, or with friends and family – a bring-and-buy, an afternoon tea, a games afternoon or a quiz perhaps?



COLLECT SPONSORSHIP – LIKE LYNDA COPSON

On 16th December, Lynda Copson ran her 100th marathon. Enough of a massive achievement in its own right – but just imagine that Lynda was diagnosed with PMR a few months ago. She thought about her fellow sufferers when she ran the event, and raised £624 sponsorship for PMRGCAuk. This was her story:

"I ran my first (and only, or so I thought!) marathon the week I turned 50. But I've enjoyed running marathons, the places I have run and the all the inspirational people I run with, and just over 5 years later I am about to run my 100th marathon. Earlier in 2017 I started to experience mobility problems (particularly in the neck and hip)

meaning my walking and ability to sit was hampered, yet being the stubborn person I am I persevered with my marathons (at times struggling to walk the distance). After blaming it on other things (e.g. over-training) I went to my doctor in July. PMR was diagnosed and I am now managing the condition, and am back to pre-diagnosis mobility."

What a complete inspiration!

If you or a member of your family would like to take on a sponsored challenge to raise money for PMRGCAuk, then you can set up a personal fundraising page here: <https://uk.virginmoneygiving.com/fund/PMRGCAukappeal>



APPLY FOR MATCHED FUNDING

PMRGCAuk has a long list of organisations which will match the funds raised by their former and current employees. Visit www.pmrzca.co.uk/content/matchedfunding to see which companies take part in fund-matching schemes and you can double the money you have raised.

WE CAN HELP

If you are running any fundraising event – however large or small – we can help. If you would like any support, for example posting information on social media to help publicise it, please email kathryn@pmrgca.org.uk

HAPPY 10TH BIRTHDAY TO US!

On 14th March 2008, an inaugural meeting took place in London between representatives of all the known PMR and GCA support groups around the UK, plus several interested individuals. They were among the founders of what became the charities of PMRGCAuk, PMR-GCA Scotland and PMR-GCA North East Region Support. The photo shows some of the people who were at that first meeting.



It is thanks to all those early trailblazers that we are here ten years later, going from strength to strength! We will be celebrating the anniversary at our Members' Day in September and have launched a tenth anniversary fundraising appeal to transform the service we offer to people with PMR and GCA: <https://uk.virginmoneygiving.com/fund/PMRGCAukappeal>

Our small charity, dedicated to supporting people with PMR and GCA, needs more funds

On the occasion of our tenth anniversary, we have launched a major appeal to raise £50,000 to extend our work.

Each year in the UK an estimated 50,000 people are diagnosed with PMR and a further 12,000 with GCA.

Over the past decade, with your support, we have done so much. But now, as more and more people find out about us, we need to raise more money to help them.

WHAT WE NOW NEED TO DO

PMR is the most common inflammatory disorder among older people. Undiagnosed or wrongly treated GCA is one of the most common causes of sudden sight loss. We need to step up action:

- Build the network of Support and Meet Up groups – from across the country, you are asking for more groups to be organised.
- Organise telephone meet-ups for those unable to get to meetings.
- Develop educational resources – including for members and their families, but for others too, including employers. Too many people with the condition face losing their jobs through their employers' ignorance.
- Go out and educate medical students, doctors and health professionals.
- Step up public education through radio, newspapers, television and online.

We need to employ a full-time director, and a full-time membership secretary/administrator alongside other support to provide educational materials and outreach work.

We don't have an office and our overheads are very low. All the money you give will go directly to pay for staff time this year and next.

Read the full text of our ten year anniversary appeal here: www.pmrzca.co.uk/content/ten-year-appeal

HOW YOU CAN HELP

Please make a donation to our tenth anniversary appeal. Send a cheque payable to PMRGCAuk to BM PMRGCAuk, London WC1N 3XX or donate securely online at: <https://uk.virginmoneygiving.com/fund/PMRGCAukappeal>

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



Photograph: © Neil Roberts

APPLY NOW FOR PROFESSIONAL MEMBERSHIP

Professional membership of PMRGCAuk is now available free of charge to consultants, registrars, GPs, registered nurses, pharmacists, chartered physiotherapists, ophthalmologists and medical students, with an interest in PMR and/or GCA.

Professionals can sign up online here: www.pmrzca.co.uk/pro_membership-application/

For more information contact: prof.membership@pmrgca.org.uk or 0300 999 5090

MUCH-NEEDED NEW DATABASE MADE POSSIBLE DUE TO A LEGACY

Behind the scenes, we are always working hard to ensure that the information we hold about our members is safe, secure and that we are following data protection rules and best practice. This includes the new General Data Protection Regulation (GDPR) which comes into force on 25 May and which you may already have heard about in the news.

As part of our commitment to looking after your personal information, in January 2018 we started to use a database called Salesforce and their charity-focused 'Not For Profit Success Pack'. This is an excellent system that is used by 150,000 organisations worldwide and which offers free licenses to charities – 28,000 charities, large and small, have taken them up on this offer since they started.

Setting up the new system and moving our data over securely was a complex job which required many hours of dedicated work by Laurene Brooks and professional assistance from a database developer. This was only possible due to a legacy from the late Stella and Jack Satchell.

FAREWELL TO LAURENE AND CLAIRE

It's all change at PMRGCAuk.

Membership Secretary Laurene Brooks, who joined the charity as our Membership volunteer back in 2012 and became a staff member in 2015, is retiring at the end of April. Laurene has done an outstanding job developing our Membership programme from its very early days, right through to the newly implemented Salesforce database system. Her brilliant organisational skills and the care with which she looked after our members have been such an asset to the charity. Recruitment for her successor is underway.

Outreach Coordinator Claire Jones's 18-month contract came to an end in March, as we unfortunately reached the end of funding for her post. As well as supporting our wonderful Group Organisers, running a successful pilot of telephone meet ups and contributing to organisational strategy, Claire has written and produced an excellent handbook of resources for Group Organisers, which I know we will be using for years to come.

Both Laurene and Claire have made a huge contribution to PMRGCAuk. We will miss them and would like to thank them and wish them all the best for the future.

Kathryn Busby, Director

PMRGCAuk
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



GCA IN SCOTLAND

In recent years it has been recommended that suspicion of GCA by any health professional should lead to immediate treatment with a protective dose of steroids followed by prompt onward referral to an appropriate specialist (the Fast Track Pathway). From Helpline calls and discussion with members, we know that this is not yet happening in much of Scotland. Sometimes this is due to geographical remoteness from consultant care and sometimes due to reluctance in primary care and A&E to start steroids without a definite diagnosis. When this leads to avoidable sight loss it is a disaster for the patient and a failure of our system.

PMR-GCA Scotland has worked hard these last two years to increase awareness of the illness and best practice in its treatment among GPs, ophthalmologists and A&E staff, including hosting a conference in Glasgow, bringing the Rheuma Research Roadshow to Kirkcaldy and liaising with Fife Rheumatic Diseases Unit.

In November, Dr Jane Gibson, supported by half a dozen members of the charity, described to the Holyrood Cross Party Group on Arthritis and Musculoskeletal Conditions the work she had done to reduce sight loss in GCA patients seen at Whyteman's Brae Hospital by introducing a Fast Track Pathway. This provides GPs with a telephone hotline to the rheumatology department or, if there are already visual symptoms, to ophthalmology who then consult with rheumatology. At the same time the patient is started on steroids, protecting their sight. Usually they are seen by a specialist within 24 hours and the diagnosis is then confirmed by ultrasound or Temporal Artery Biopsy. This has resulted in:

- improving the speed of referrals
- ensuring all patients are referred to rheumatology
- reducing the need for temporal artery biopsies by 64%
- reducing potential harm from steroids by having fewer misdiagnoses
- eradicating sight loss (as at November) during 2017

These results mirrored those achieved by Professor Dasgupta in Southend.

At the meeting of the CPG it was agreed that a letter would be sent to the Health Minister, drawing her attention to the above example of good practice and the resulting benefit for both patients, the NHS and Social Care, where there are obvious cost savings by avoiding the consequences of sight loss in an older person who might have to go into care or a younger one who has to give up work. The Minister was asked for figures on the numbers of those in Scotland who lost sight due to GCA and to give support to rheumatology departments to enable staff training and ultrasound machines to be provided. Her response will be followed up after it has been given at the March meeting of the Cross Party Group.

OUR VOICE IN SCOTLAND

Healthcare Improvement Scotland encourages us all to become involved and share our voices as patients to make health and social care better for all.

When an issue affects the membership, like that of improving treatment for those with GCA, the charity can take action at national level as described above, to bring to the Government's attention the experiences and wishes of our members. In a few months we shall also be making a submission to the



HELPLINE

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Scottish Medicines Consortium (SMC), the national body which decides whether a drug can be licensed for use by the NHS in Scotland. An application is being made for tocilizumab (remember this from the GiACTA trials in which some members took part) to be used in GCA. Those who are active on PMR-GCA forums e.g. Patient UK and HealthUnlocked will know that this drug is much talked about by patients from America where it is already licensed and is allowing some to achieve stable remission while taking less than 5mg steroids, less than a year from diagnosis.

When asked to do so we will provide a submission on the experiences of those living with GCA and also those caring for family members with the illness. For this, we need members to send us stories and quotes to give a picture of what it is like – especially the problems faced by those with other medical conditions which make taking steroids so difficult, or who have had severe side effects from steroid use, or who have just not responded well enough to achieve remission after many long years of trying to reduce.

Please, please give us your thoughts through any of the usual ways of contacting the charity so that, whatever the decision of the SMC, our voice will have been heard.

OMERACT

asks for our help

Many readers will remember previous articles from members who have worked with the international organisation of health professionals who produce Outcome Measures in Rheumatology (OMERACT).

Each time, it was the importance that OMERACT placed on patient input that made the greatest impression.

Now OMERACT's PMR working group is asking for help from members of PMRGCAuk and PMR-GCA Scotland. Dr Max Yates from the University of East Anglia would like volunteers who have or have had PMR to go online and look at some different ways of measuring the severity of major outcomes in PMR: pain, stiffness, quality of life and inflammatory markers. They will then be asked to fill in a short questionnaire on each. This should take only about ten minutes and you may choose to complete just one or all of the items.

If you would like to take part in this anonymous survey please go to www.pmrzca.co.uk/content/omeract where much more information is available. Those of you who use the forum HealthUnlocked will also find an invitation there. The closing date for responses is the end of July 2018.

I hope that, as patients, we can make the most of this opportunity to have our voices heard and can provide Dr Yates and the OMERACT working group with the information they need to help them select the best choice of Outcome Measure in each case.

We look forward to seeing the results reported in NewsWire at a later date.

Lorna Neill is Chair of PMR-GCA Scotland



Margaret Grover



SCLERODERMA & RAYNAUD'S UK

In the summer 2017 edition of NewsWire, we featured an introduction to scleroderma and Raynaud's and the charity Scleroderma & Reynaud's UK (SRUK). PMRGCAuk member Margaret Grover, a retired tax advisor from Kent, got in touch to share her experience of Raynaud's and how this was the first sign of another condition. She talked to SRUK:

"I have had Raynaud's symptoms for probably at least 20 years, and it has gradually got worse. In 2005 I had frequent throat problems; blood tests at that time led the ear, nose and throat (ENT) consultant to refer me to a rheumatologist, who diagnosed Sjogren's and scleroderma. In 2015 I had difficulty walking and was diagnosed with spinal stenosis. I then developed polymyalgia rheumatica (PMR) which was extremely painful and is treated by steroids. I had lumbar surgery in 2016, but I still cannot walk very far due to the combination of stenosis, PMR and the steroids. I have never seen a rheumatologist for PMR – it is managed by the GP alone.

The diagnosis of Raynaud's was not unexpected, as my mother had it. It is less of a problem in summer, but opening the freezer door and venturing outdoors in winter must be managed carefully! Disposable hand warmers are wonderful inside gloves and boots with furry linings have been brilliant for winter.

The rheumatologist I saw in 2005 told me there was no specific treatment for Sjogren's and Raynaud's and just to learn to live with it. She said that nifedipine might improve the Raynaud's but as my blood pressure was on the low side it made me feel light headed and dizzy. The ENT consultant said that drinking water was as good as anything to help with the dry throat and difficulty eating dry food. I have had acupuncture and massage over the years which do seem to help.

The most debilitating aspect of my life is PMR and the side effects of taking steroids. I take one day at a time, really – some days are better than others."

For more information on Raynaud's and scleroderma and to take an online test, visit sruk.co.uk/testme



CONGRATULATIONS TO OUR WINNING CHRISTMAS CARD DESIGNERS

We are delighted to announce the winners of our recent competition to design a PMRGCAuk Christmas card.

Winner: 'Christmas Eve' by Susanne Meyers.

Joint runners up: 'Peace and Happy Nest' by Lorna Cann and 'The Holly & the Ivy' by Rosemary Hurry.

Congratulations and thanks to Susanne, Lorna and Rosemary! Their designs will be used for our 2018 range.



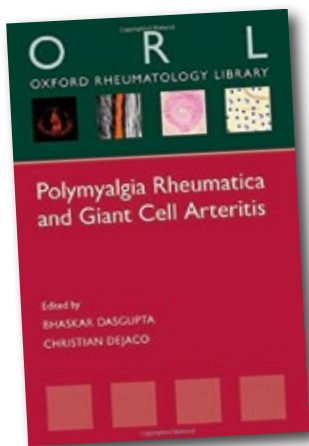
'Christmas Eve'
by Susanne Meyers



'Peace and Happy Nest'
by Lorna Cann



'The Holly & the Ivy'
by Rosemary Hurry



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.



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.

Write Me Funny...

by Mark Benjamin

Following his popular, humorous blog on the PMRGCAuk HealthUnlocked forum under the guise of markbenjamin57, Mark's witty ramblings are now available as a paperback book. 'Write Me Funny...' is intended as an antidote to the important but often serious publications about PMR/GCA. Cartoons by Anthony Allen bring the content alive, making the book a 'must read' for PMR and GCA survivors who want something light-hearted and different.

'Write Me Funny...' is available initially as a paperback book exclusively via PMRGCAuk with 25% of the net sale proceeds donated directly to the charity in appreciation of its support. To find out more and order Mark's book, which is now available to purchase online, go to www.pmrzca.co.uk/content/book



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)
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WALES

CARDIFF SUPPORT GROUP

Contact: Sue
cardiff@pmrgca.org.uk

NORTH EAST ENGLAND

PMR & GCA UK NORTH EAST SUPPORT GROUP

Contact: Mavis Smith
www.pmr-gca-northeast.org.uk
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NORTH WEST ENGLAND

ILKLEY MEET UP

Contact: Sue
ilkley@pmrgca.org.uk

KENDAL, CUMBRIA MEET UP

Contact: Win Sayers
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MIDLANDS ENGLAND

COVENTRY MEET UP

Contact: Ann Hollingsworth
pmrgca.coventry@gmail.com

EAST MIDLANDS SUPPORT GROUP

Contact: Bridget
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SHROPSHIRE SUPPORT GROUP

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EASTERN ENGLAND

BEDFORDSHIRE MEET UP

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CAMBRIDGE SUPPORT GROUP

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EAST ANGLIA SUPPORT GROUP

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PETERBOROUGH SUPPORT GROUP

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SOUTHEND/ESSEX SUPPORT GROUP

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WOODBIDGE MEET UP

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SOUTH WEST ENGLAND

BATH MEET UP

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BRISTOL GROUP

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CAMBORNE MEET UP

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CHRISTCHURCH MEET UP

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PLYMOUTH AND CORNWALL SUPPORT GROUP

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PORTISHEAD MEET UP

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SALISBURY MEET UP

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SOUTH WEST (TAUNTON) SUPPORT GROUP

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TORBAY MEET UP

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GREATER LONDON, ENGLAND

GREATER LONDON SUPPORT GROUP

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BARNET MEET UP

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HIGH WYCOMBE MEET UP

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SOUTH AND SOUTH EAST ENGLAND

BRIGHTON MEET UP

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CHICHESTER MEET UP

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HASTINGS MEET UP

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PORT SOLENT MEET UP

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SEVENOAKS MEET UP

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SURREY SUPPORT GROUP

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WORTHING SUPPORT GROUP

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worthing@pmrgca.org.uk

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