



INSIDE THIS ISSUE

- 02** VOLUNTEERING ON THE TELEPHONE HELPLINE
We need you!
- 03** RESEARCH ROUND UP
- 04** ACROSS THE COUNTRY
News from the groups
- 05** A PHOENIX RISES FROM THE ASHES IN THE NORTH EAST
Mavis Smith shares the story of the charity and what to expect next.
- 06** ROUNDING OFF THE ROADSHOWS
Kate Gilbert takes stock of the Rheuma Research Roadshow
- 07** NEWS FROM SCOTLAND
Lorna Neill reports
- 08** FUNDRAISING & AWARENESS
PMRGCAuk Week 2019 and other fundraising stories
- 10** SHARE YOUR STORY
Raising Awareness as a Trustee – a personal experience
- 11** SHARING EXPERIENCES ONLINE
The PMRGCAuk online forum
- 12** SUPPORT GROUPS
All the contacts you need

 **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.

All set for PMRGCAuk Week

PMRGCAuk Week will take place this year between 18-24 June.

Now in its 3rd year, it is becoming a regular feature in the PMRGCAuk calendar, providing an opportunity for Groups and Members around the country to raise awareness and vital funds. This year's event has been planned to coincide with Small Charity Week, which celebrates the essential work of the UK small charity sector, in the hope of gaining even more

momentum. Candy Horsbrugh, Deputy Director, who is supporting Groups who want to take part said,

"By joining in with Small Charity Week, we hope we can take our campaign to a new level. Our Groups have always risen to the challenge and we hope this year to see even more events being organised and people taking to social media to spread the word about the difference we are making to them."

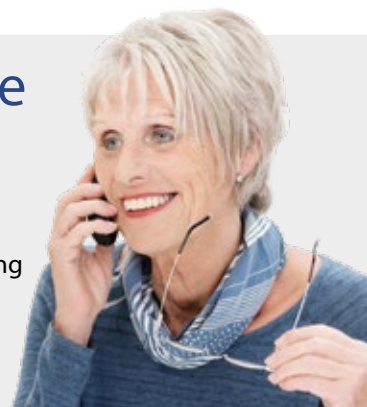
Want to get involved?

Find out more on page 8.

"I enjoy the feeling that I have really helped someone"

We need you!

The Telephone Helpline takes hundreds of calls a year, helping those who need support and advice. Find out more about what it's like to volunteer on the Helpline and the difference it's making to those who call. **See inside on page 2.**



Great Grandmother's 30 mile Canoe Challenge



Eileen, a 78 year old great grandmother from Malvern, suffers from both PMR and GCA. Together with her husband Ken, she is preparing to paddle 30 miles along the Birmingham to Worcester canal to raise awareness of both conditions and funds for PMRGCAuk on 7-9th May. The event, which has taken weeks to prepare for, involves paddling 30 miles, in 3 days, with 57 locks and 5 tunnels as obstacles. The canal also has one of the largest lock flights in Europe – the 30 Tardebigge Locks that climbs 428 feet. (Read the full story on page 9.)

Save the date

MEMBERS' DAY: SATURDAY 7 SEPTEMBER 2019, LONDON



Volunteering on the Telephone Helpline

“I enjoy the feeling that I’ve helped someone”

The PMRGCAuk Helpline deals with over 400 calls a year, offering support and advice, as well as lending a friendly ear. Staffed by six volunteers who have experience of either PMR, GCA, taking steroids or caring for someone with either condition, the service is highly valued. Trish Galli, 72, spoke to us about her experience as a volunteer on the Helpline. “I first developed PMR when I was 58. It lasted for nearly 3 years, went away but then recurred. I started volunteering then with the Helpline, giving a day a week. I wanted to help as I have a long history of PMR. We can’t offer medical advice, but I think many people who call are looking for reassurance that they are not alone and we understand their worries because we have all had them! That is often enough to reassure people that they will come through it.”

Trish knows that steroids are often a source of concern, “Apart from reassurance and support, a common theme is also medication. A lot of our callers are very fearful of taking steroids and need reassurance. They have concerns about Prednisolone dosage in particular – either they have reduced and then got symptoms back or want to know how to reduce safely.”

While volunteers aim to answer the majority of calls “live”, it is not always possible and those calling are encouraged to leave a message, so that calls can be returned – typically the same day. The team are always keen to talk to new volunteers to

help meet the growing demand and without them giving up their time, it would not be possible to offer this valuable service. The rewards for Trish are clear “As well as being able to help others, you will also be surprised how listening to other people helps you as well! There are a lot of very frightened people who are given their diagnosis, put on steroids and sent away to get on with it. The doctors don’t have time and some don’t have the knowledge to explain that it isn’t such a terrible thing and they will recover. I enjoy volunteering and feeling that I have really helped someone.”

And what about those who call the Helpline? Roger Church was guided to the Helpline after his daughter found the details online, “I called the Telephone Helpline and felt so much better afterwards. I can’t tell you how much difference it makes to speak to others who have had the condition, who know what it’s like and can share their own experiences. I know you can’t give medical advice, but I was directed to a paper on the website by a top Rheumatologist. It gives you the tools to go back to your doctor and discuss things, like your dosage.”

WE NEED YOU!

If you would like to volunteer for the Telephone Helpline, please email chris.young@pmrgca.org.uk to arrange a time to speak.



PHONE BUDDY SYSTEM UPDATE

Preparations are underway to set up the telephone ‘buddy’ support for people with PMR and GCA who don’t have access to a local Support Group or who can’t get to it. Guidelines for people wishing to volunteer to be a Buddy and for those who are requesting support from a Buddy are being put together, as well as application forms for both parties to ensure people with similar experiences are put in touch for the best outcome. If you are interested in volunteering to offer support or would like the support of a buddy, find out more by contacting candy@pmrgca.org.uk





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

RESEARCH ROUND UP

Almost all of the published research in the last few months has been about polymyalgia rheumatica (PMR), rather than giant cell arteritis (GCA).

We have new, up-to-date estimates of how common PMR really is and for how long people are treated with steroids¹. Using a really large dataset, it has been shown that in people over the age of 40 in the UK, around 96 in every 100,000 people will develop PMR in a given year. This was higher in women, in older people and in people living in the south of England. In 2015, around 85 in every 1000 people over the age of 40 had ever been diagnosed with PMR. The average time taking steroids was 16 months, but 1 in 4 people took them for more than 4 years.

Researchers in Denmark have been looking at whether people who get PMR and GCA have a stronger immune system, which they defined as having fewer infections before they got PMR or GCA². The only association they found was in the year before PMR or GCA diagnosis, and so they could not be sure that this association wasn't due to early symptoms of PMR or GCA being treated as an infection. They say this is evidence against the 'hyper-immunity' hypothesis as a cause for PMR.

Really positively, there has been a lot of interest recently in the patient perspective on PMR. First, a survey of primary care patients with PMR has reported that they want researchers to prioritise finding better treatments for pain, stiffness and fatigue, improving diagnosis, and of course, managing steroid treatment³. Second, the OMERACT (Outcome Measures in Rheumatology) special interest group for PMR, led by Dr Sarah Mackie and including patient representatives, has come up with a 'core outcome set'. By this, they mean the things that should always be measured in studies of PMR and how to measure them⁴. Chosen domains are pain, stiffness, physical function and blood markers of inflammation. This work is key if we are to be able to properly test any new treatment options.

In relation to treatment, researchers in Japan have tried a drug called Mizoribine as a potential alternative to Methotrexate in people who need help to reduce the amount of steroids they are taking⁵. The results looked promising, but it was a very small study and other studies using more appropriate methods will be needed before this drug could be used more widely.

There has also been another, relatively small study from Italy that suggested that taking a certain type of bone protection drug alongside steroids (which many people with PMR already do) might reduce the length of time people need to take

steroids⁶. Again, we will need much more research to find out if this is the case. It might just be for example, that people who get these bone protecting drugs also get more help from their doctors to reduce their steroids.

Finally, thinking about doctors, a combined survey and interview study with GPs has reported that GPs often find it difficult to diagnose PMR⁷. Although they largely follow the guidelines, they still find PMR difficult to diagnose accurately and they share the concerns of many patients about steroids.

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ACROSS THE COUNTRY

EAST MIDLANDS GROUP

A dietitian, also a trained nutritionist, gave a talk to the Group in March. With members coming from a wide geographical area, the whole group meets once or twice a year, with smaller, informal meet ups, every two or three months in Derby, Southwell, Nottingham and Meadowhall. For further information contact Bridget eastmidlands@pmrgca.org.uk

ILKLEY GROUP

Dr Sarah Mackie, Rheumatologist and Associate Professor, University of Leeds, gave an informative talk entitled "PMR and GCA Research – What's Next" at the Ilkley Group meeting in September, giving all a better understanding of drug research and clinical trials. The meeting, with the best attendance so far, had people travelling from Lancashire, as well as North and South Yorkshire.

WORTHING SUPPORT GROUP

Group members enjoyed two very interesting and interactive sessions in December and January. Mike Slator, a local pharmacist, spoke about the various medications those with PMR or GCA might encounter and Diane Mason, a local optometrist, led a fascinating discussion on eyes, including demonstrating with a large scale model of the eye 'how it all worked'. The Group meet on the second Tuesday of the month at Durrington Community Centre.



SURREY GROUP

After ending 2018 with Surrey Group members being entertained at their Christmas party by a guitarist playing popular 60's music, the first meeting of 2019 got off to a great start with an enjoyable presentation by Mark Benjamin, author of 'Write Me Funny....Ramblings on the Lighter Side of PMR and GCA'. With 25% of each book sold by Mark being donated to the charity, it's also an excellent way to fundraise.



ORPINGTON GROUP

Orpington members learned about the benefits of Nordic walking and had a chance to have a go themselves, walking with the help of poles. A group is now arranging to take a course with instructor Ruth Jones of Nordic Walking UK. There are Nordic walking groups across the United Kingdom – find out how you can benefit at www.nordicwalking.co.uk And a poem to share is below...

*We meet at St Paul's in the Crofton Road
Sharing the journey lightens the load.
Our speakers are varied; the talks they give
Help us improve the way that we live....
with our conditions*

*Christmas lunch in November – we're ahead in our year –
was at the Black Horse and full of good cheer!
We don't meet in December we need a bit of a break
But we still take our meds and most nights we're awake!
it's the conditions*

*In January members and guests arrived from afar
to hear Orpington's new rheumatology registrar
Amanda answered questions for an hour or so
on flares, meds and treatments and heard all our woes
about our conditions*

*Nordic Pole walking in Feb led by Ruth Jones
Will get us all active and build up our bones
we all know we need to exercise longer
use the old muscles to make them much stronger
and improve our conditions*

A phoenix rises from the ashes in the North East

The end of last year saw the closure of the PMR & GCAuk North East Support registered charity. Former chair, Mavis Smith, shares the story of the charity and what to expect next.

"On 14th March 2008, 25 people met in London. Twenty-two were patients with PMR, GCA or both, and the chair of the meeting was Professor Bhaskhar Dasgupta. The meeting resulted in the decision to form the PMRGCAuk national charity." Two of the patients present, Mavis Smith and Pam Hildreth, on returning to the North East established the North East Support Group. "We received encouragement from other patients and two consultants and within a year we became the PMR & GCAuk North East Support registered charity, with patrons including Dr. Saravanan Vavidelu, Dr. D Anderson and Professor Bhaskhar Dasgupta."

A FANTASTIC LEGACY

Over the next few years the charity went from strength to strength, "Our wonderful trustees all brought their own individual attributes, skills and personalities to this vibrant NE charitable organisation – Margaret Wright, Lynne Boyle, Christine Beet, Alan Tailford and John Robson, all joining Pam and I as Trustees. For the past 10 years, the Group has been extremely dynamic and has left a

wonderful legacy, including a range of valuable resources and information – from the website, regular newsletter and steroid record booklet with an alert card, to our "You are NOT Alone" DVD and the "Living with PMR & GCA" booklet."

Membership grew to around 200, four well attended meetings were held each year at each of the two main venues and the Group raised funds for projects including supporting a GCA research student (£9,000) and the NHS research project "Your Ears" (£1,000).

PHOENIX RISING

In October last year, with the current trustees sadly unable to continue, a decision was made to close. But there are new beginnings to look forward to, "The North East charity's assets of over £13,000 have been transferred to PMRGCAuk the national charity. Plans have been made to continue to support previous North East members through the PMRGCAuk membership scheme. We are also delighted that, in agreement with their chair, £10,000 will be used specifically for a two year GP training project in the North East and North Cumbria."

In addition, John Robson, one of the former trustees, continues the 10 years of work of the NE charity, leading a new PMRGCAuk Support Group, under the auspices of the national charity, the first meeting of which took place in Durham City in March.

To find out more about future plans to support those in the NE, please visit www.pmrzca.co.uk/group-pages/northeast/ or contact John Robson on 07470 506 667 or email northeast@pmrgca.org.uk



The North East Group



Pam Hildreth



Mavis Smith



GETTING TO KNOW JOHN ROBSON

John is 57 and in remission from Polymyalgia Rheumatica. In 2013 he was diagnosed with PMR when still a serving Fire and Rescue Service Officer, due to run his 5th London marathon and climb Ama Dablam in the Himalayas. Instead, John rigidly followed his 21-month steroid reduction programme and whilst still on steroids completed his 15th Great North Run, raising valuable funds for the PMRGCAuk NE Charity and the BBC and ITV following his progress. John is no stranger to supporting the work of charities and going the extra mile to fundraise, as a founder member of the Fire and Ice Expeditions team that has donated over £140,000 to local children's charities, he has climbed five of the world's seven continental summits, survived 30+ expeditions, and delivered many inspirational and motivational presentations.



Rounding off the Roadshows

Kate Gilbert, one of the 'PMR Fighters' who helped to set up PMRGCAuk, went on to lead the successful Rheuma Research Roadshow in 2017-18. She takes stock of the experience and highlights the achievements.

The project, funded with a small grant from the Wellcome Foundation, was possibly the most ambitious single venture taken on by the charity in its short history. "The concept was to take up-to-date research on PMR and GCA to various sites around the country. There were three main aims. The first was to increase knowledge and awareness of the two conditions

and relevant research, among patients, carers and the public. The second, to give a 'platform' to researchers to present their work to patients in person. The third, to collect current material that could be used in training and education in future, both for patients and clinicians."

Reporting back to Wellcome at the end of the project, "We were able to say that although we had not quite fulfilled one of the outcomes, we had exceeded expectations on others. The roadshow events, 11 in all, were a huge success, attracting sizeable audiences in all the venues. Thirty-two researchers and clinicians from around the country participated, together with hundreds of patients and their partners. PMRGCAuk is now at the centre of a thriving research network and we are seen as the 'go-to' organisation for patient representation, which is so important in today's tight research funding environment. We have also given lots of young researchers their important first taste of presenting their work."

Analysis of all the feedback forms indicated there was almost 100% satisfaction throughout with the quality of the presentations and discussion, "By any standards this has to be a success!"

Plans to develop an online course for doctors may have proved a bit over-ambitious but are now providing a foundation for future thinking, "Along the way we realised that to develop a course that would carry accreditation for clinicians would require a new project. We are working on plans for this at the moment. However, all the material we collected will be put to good use in short videos and other items to be published from time to time. There's a lot of it and it all takes time – but we are getting there!"

With PMRGCAuk on record as having successfully delivered on a project funded by a major donor, the way is now paved to stand us in good stead for future bids.



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

MORE ACCESS TO ULTRASOUND

On Friday 23rd November 2018 the Chair, the Secretary (and photographer) and Liz Benneworth a member from Perth with GCA who just happens to be Mrs. Secretary, travelled to Dunfermline Royal Infirmary where Fife rheumatologists had gathered for an "awayday" meeting. We were there to present a donation from the charity to Dr. Sarah Hailwood, Lead Consultant Rheumatologist from Fife Rheumatic Diseases Unit at Whyteman's Brae, Kirkcaldy. The money was to be used to train another consultant in ultrasound diagnosis of GCA.

I thanked the staff for their support for the charity in our attempts to raise the profile of PMR and GCA within the medical community and to improve the diagnosis and treatment available to patients. Liz then made the presentation to Dr. Hailwood and of course we wanted to capture the moment with a photograph – isn't it remarkable how difficult it is to capture three people and find a shot in which all look acceptable!



Presentation to Fife Rheumys

FUTURE RESEARCH

At support group meetings, on the helpline and by email we get asked questions about both PMR and GCA for which no answer can be given because there is no convincing evidence available from medical research.

It is not easy, and often expensive and time-consuming, to find out whether our own individual experience, or even what we hear from small groups at meetings or online, is actually still true when put to the test of a properly conducted medical trial. It can also be difficult to accept that what seems to work for us as an individual may seldom work for others. Because of this emotional investment in our own experience it is important that we support researchers who are unbiased and make it possible to distinguish between advice based on what might be true and that which has been shown to be true over time and for large numbers of patients. This means that when asked if we are prepared to take part in a clinical trial of a treatment or medicine we should be prepared to say yes. It is not easy to recruit enough patients to get meaningful results, especially when the illnesses, as in PMR and GCA, are not common.

It would be interesting to know the views of our members about what you consider to be the most important questions needing to be answered by future research.

Please email suggestions to info.scotland@pmrandgca.org.uk or phone the Helpline on 0300 777 5090.

AGM

The 2019 AGM took place on Friday 12th April, with speakers Kate Gilbert, author of Polymyalgia Rheumatica and Giant Cell Arteritis – A Survival Guide and Mayrine Fraser of the National Osteoporosis Society. Thank you to all of you who came along and made it such a great event.

ABERDEEN GROUP

The views of members in Aberdeen and the surrounding area are currently being sought to find out if an Aberdeen support group would be of benefit.

If you would be interested in learning more please contact David Carrott: aberdeen@pmrandgca.org.uk tel: 01479 8321400.



HELPLINE

0300 777 5090

www.pmrandgca.org.uk

Registered Scottish Charity No SC037780

Registered address
7 Hamilton Place, PERTH, PH1 1BB

PMRGCAuk WEEK 18-24 JUNE 2019



COLOUR RUSH!

In May Trustee Janice Maddock and 5 members of her friends and family will take part in the **5K Colour Obstacle Rush** to fundraise for PMRGCAuk at Royal Windsor Racecourse. The 'Colour Obstacle Rush' is a unique event combining the fun of colour powdered runs, the thrill of an obstacle course and the atmosphere of a music festival. Janice, who has PMR herself, can put others minds at rest who might want to take part in a future event near them, "Although this is a 'running' event, you don't have to run if you don't feel like it. In fact, usually there are as many people walking (or dancing) through the course as running!"

If you would like to sponsor Janice's team please go to their fundraising page: <https://uk.virginmoneygiving.com/JaniceMaddock1>

"Thank you for helping us to raise much needed funds for this worthwhile cause close to our hearts."

NEW FUNDRAISING EVENTS PROGRAMME

A new fundraising events programme was launched in March to continue to add to the 10th Anniversary Appeal. The first event, which took place in London, with guest speaker Cathy Newman from Channel 4 News, was sold out. Penny Denby, former Chair of PMRGCAuk, who is now focusing on organising the fundraising events programme said, "With such a fantastic start, I'm looking forward to building momentum with other events. We hope to do three big events each year and are always delighted to hear from people who have ideas – or contacts – who can help us."

Groups around the UK are gearing up to raise awareness and funds as part of PMRGCAuk Week.

Now in its third year, members and supporters are getting used to this fantastic opportunity to shout about our small charity and the impact we have. If you want to get involved, email candy@pmrgca.org.uk and look at the information online www.pmr-gca.co.uk/content/pmr-gcauk-week.

3 SIMPLE IDEAS TO GET YOU STARTED



Afternoon tea

Invite three or four of your family, friends or neighbours to join you for afternoon tea. Tell them about PMR and GCA and ask them to make a donation to the charity. That's it! Simple, enjoyable and very effective.



Sponsored walk

The beauty of a sponsored walk is that you can adapt it to suit you. Get together with friends and family and choose a picturesque or historically interesting route. Then collect sponsorship using our paper forms or online. If you prefer, adapt the sponsored walk into a sponsored cycle or swim. You can sign up for a sponsorship web page at uk.virginmoneygiving.com and collect donations online.



Quiz night and raffles

Quiz nights can take place with a few people at home or with more people in a local hall or pub. It's not always about getting the questions right, but having fun with friends and family while raising a bit of money. You can charge an entrance fee (it doesn't have to be much), have a donations box, have a raffle. The Quiz Night prize could be a box of chocolates, or a nice bottle of wine. You can find links to Quiz night questions at:

www.pmr-gca.co.uk/content/pmr-gca-week



GREAT GRANDMOTHER'S 30 MILE CANOE CHALLENGE

Eileen Allcock, a 78 year old great grandmother is preparing with her husband Ken, to paddle 30 miles on 7-9th May along the Birmingham to Worcester canal to raise awareness of PMR & GCA and funds for PMRGCAuk.

The challenge involves paddling 30 miles, in 3 days, with 57 locks and 5 tunnels as obstacles. The canal has one of the largest lock flights in Europe – the 30 Tardebigge Locks that climbs 428 feet, but luckily Eileen and Ken will be going down this carrying their canoe, rather than navigating each lock!.

The trip was devised on the way home from PMRGCAuk's AGM in September 2018, as they wondered what they could do to support the charity. Over the last 30 years, Eileen and Ken have paddled extensively,

mainly on rivers and lakes in England, Wales & Northern Ireland and once down the Whanganui in New Zealand. Having more recently limited their water activities to occasional fine-weather paddling on local rivers, the idea to mount this 30 mile campaign seemed like a challenge, as well as the potential for a lot of fun.

Preparation has taken weeks, "Part of the planning has included walking along the canal, that neither of us know very well, and working out where to stay and where to store the canoe overnight. We have been delighted by how helpful people have been – I asked a shopkeeper if he could suggest a place nearby where we could leave the canoe, and he offered not only to store it in his shop, but also to drive us to our accommodation that night, and pick us up the next morning to resume!"

One of the tunnels that they need to navigate is 1.5 miles long. Too long to canoe through, and over 3 miles to walk over to the other side, Eileen and Ken decided to hire a narrowboat to take them and their canoe through the tunnel, and have invited people to spend a day out on the narrowboat.

Busy raising awareness ahead of their adventure with the support of Kim Main, the manager of their

retirement village, a canoe has been placed in the entrance to the village, to start conversations. Following a dress-up day at the village, they have also raised over £400 and in return the owners of the village, Fortis Living, had a dress down-day at work, raising a further £800.

"I am overwhelmed by the generosity of so many people and would like to thank the support given by friends, family and supporters."

To sponsor Eileen go to <https://uk.virginmoneygiving.com/EileenAllcock1>





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, please contact liora@pmrgca.org.uk

RAISING AWARENESS AS A TRUSTEE A PERSONAL EXPERIENCE

Janice Maddock, trustee for PMRGCAuk shares her experience with us

'When I began suffering from crippling pains and stiffness in my neck, shoulders and back in 2012, I presumed it was down to the stress of caring for my elderly mother who had passed away that year. Yet very soon everyday life became almost impossible. Pain, aching and stiffness had become a way of life for me. Soon I was unable to turn or get in and out of bed, could not turn my head, which made driving dangerous, or get in and out of the chair. I tried physiotherapy, acupuncture and even hypnotherapy as I thought it might be stress related, but with no improvement. The final straw (about 6 months later) was when I couldn't even bend down to put my shoes on and my husband Steve had to do it for me.

When I eventually sought help from my GP, I was diagnosed with Polymyalgia Rheumatica at only 55 – I had never heard of it! I was immediately put on a high dose of steroids which reduced the pain and stiffness straight away but they had side effects. I was very tired and put on weight.

I gradually reduced my steroids, but did this too quickly as my symptoms started to come back. Just when I thought I was never going to get any better and was close to 'melt down', I found out about PMRGCAuk online. They were brilliant, offering me advice and support. Until then, I didn't know anyone who had PMR and had been constantly explaining it to family and friends. Many people with PMR reduce their steroids too quickly without listening to their body and end up with the symptoms returning – I realised that was me! I found that through the charity people can share their experiences and support others.

Although I understand from speaking to other sufferers that poor awareness of the conditions means many people are left suffering in silence without getting the right help, I was lucky that I had a doctor who knew what PMR was. Looking back, my mum definitely had PMR as she had all the symptoms and had to have a lot of care, but was never diagnosed. It makes me really sad to think that she suffered.

Now as a trustee for PMRGCAuk, I focus on raising awareness amongst the over 50s, people who work with them or anyone who will listen! I have spoken to around 300 people to date, to various health professionals in my locality – the receptionists at my GP surgery, the 'Versus Arthritis' helpline staff, my local Townswomen's Guild, not to mention many more informally including my optician, friends and family.

Now 6 years on, I still have PMR but I am on a low dose of steroids and hoping that at some point I will be able to come off these altogether. While I still suffer from symptoms, they are nowhere near as bad as they used to be and I have adapted my lifestyle.

For me it's really important to try and raise awareness to ensure faster diagnosis and treatment. I'm lucky that I don't have GCA, but I'd know exactly what to do if I started to develop the symptoms.

Thank goodness for PMRGCAuk and thank goodness for stretchy tops!!'



SHARING EXPERIENCES ONLINE

If you don't have a local support group, where do you go to meet other people who have PMR or GCA, find out about their experiences, and share your own?

The PMRGCAuk online forum, that's where! Since its inception in 2011, the forum on HealthUnlocked has continued to grow. Starting with just 15 members in the first month, over 8,000 people have now joined since it started, with over 2,000 active current members.

Kate Gilbert, moderator on the forum for the last 8 years, has recently stepped down and paid tribute to the work of active members on the forum "Members of the forum are overwhelmingly friendly and supportive to one another. There is a

small but growing number of people, like 'PMRPro' and 'DorsetLady', whose knowledge and advice are lifelines to people with PMR and GCA, whether they are at the start of their journey or having a sticky patch in the middle. So much so that these two ladies won an award from HealthUnlocked for their contribution."

PMRGCAuk now have a number of people who have stepped into Kate's shoes as moderators, "It's a great community to be a part of and the forum is an essential part of what PMRGCAuk offers to those seeking support. With so many people using the forum, it does take a bit of management. On the whole, everything goes along really smoothly and there are rarely any problems. Inevitably there might be the odd misunderstanding, but usually issues are easily dealt with by a simple private message from a moderator or an administrator."



CAN YOU HELP?

PMRGCAuk now have a number of volunteers who help with the forum as moderators. If you are interested in this role, now or in the future, please get in touch to find out more. Email liora@pmrgca.org.uk. And if you haven't yet discovered www.healthunlocked.com/pmrgcauk, take a look!

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



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 EAST ENGLAND

NORTH EAST SUPPORT GROUP

Contact: John Robson
northeast@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: Pat Worthington
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.