

PMRGCAuk SEEING IT THROUGH TOGETHER NewsWire



ISSUE 29: WINTER 2019



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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.

MEMBERS' DAY 2019

Around 70 people from as far away as Scotland, Yorkshire and Somerset joined us for our AGM and Members' Day in London on Saturday 7th September. There was a full itinerary with guest speakers and time for members to chat with each other

and to the experts over lunch and in the break. It was an opportunity to catch up with familiar faces and to welcome new members too. See pages 6 and 7 for highlights of the day and pages 8 and 9 for reports on the speakers.

GUIDED TOUR OF THE WORSHIPFUL SOCIETY OF SKINNERS

After the success of the Apothecaries tour in June we are now looking forward to a tour of the Worshipful Society of Skinners on Monday 6 April 2020. It will be a wonderful opportunity to explore this stately building in central London. The Skinners are one of the City of London's Great Twelve Livery companies whose origins lie in the fur trade but over the centuries this has changed and now they are a not-for-profit organisation.

The cost is £25 per ticket. Members, family, friends and supporters of PMRGCAuk are all welcome.

If you would like to join us please email events@pmrgca.org.uk with any questions and to reserve your place.



Dates for your diary in 2020

Worshipful Society of Skinners Guided Tour: **6th April**
PMRGCAuk Week: **Tuesday 16th to Monday 22nd June**
AGM & Members' Day: **Saturday 5th September**



MERRY CHRISTMAS AND HAPPY NEW YEAR!

The PMRGCAuk office will be closed for Christmas from 5pm on 20th December to 9am on 2nd January 2020. The Helpline will be available as normal on weekdays over the Christmas period with the exception of the bank holidays: 25th and 26th December and 1st January 2020.





PEOPLE NEWS

There have been some changes within the administration staff in the last few months. Liora Ives, Director, left the charity at the end of August.

We would like to thank her for her role in the charity over the past year. Liora was instrumental in creating our 3-year strategic plan; she also set up our Fundraising Strategy and created a template for future fundraising bids. Her work with us is invaluable and she leaves a strong and committed legacy. We wish her all the best for the future.

CANDY HORSBRUGH

As many of you will know Candy was our Deputy Director and has now taken on the position of Director. Her role is to work on the strategy, evaluation, fundraising and financial management of the charity, with the support of our trustees. She continues to work with our national groups, volunteers and lead on new projects such as the Buddy Telephone Support Service. She works 3.5 days a week, from Tuesday afternoon to Friday.

FRAN BENSON

Fran has been our Membership Secretary for the past 18 months and has now taken on the additional role of Assistant Director taking responsibility for NewsWire and working on marketing projects. She works 2.5 days a week: all day Monday and Tuesday mornings (for membership administration and queries) and Thursdays (for everything else).



THE PORTSOKEN WARD SUPPORTS PMRGCAUK

When Judi Sanders came to our Cathy Newman charity lunch in March she knew nothing about PMR or GCA. She enjoyed the afternoon as a guest of Dorothy Luke and mutual friend of trustee, Janice Maddock. But she was so touched by our charity that she wanted to do something to help us.

Judi has recently been made the Master of the Portsoken Ward Club. She explains "The Romans divided the Square Mile within the City of London into 25 Ward Clubs

We are The Portsoken Ward Club, a community focused club based in Aldgate. We organise affordable events for people to attend and membership is just £20 a year. We have a President, Master, Secretary, Treasurer and four Wardens. We meet once a month and we are all volunteers."

Judi continues, "Each Master can choose their own charity to support. This year I have chosen PMRGCAuk as I feel this to be something that needs to be broadcasted widely as we could all get these awful conditions."

Janice Maddock attended their



Judi Sanders (left) with Janice Maddock

AGM in June and was on hand to explain about the charity and the conditions to those who had not heard of it.

In August, Dorothy Luke kindly hosted an afternoon tea (with prosecco and cake) in her garden and 23 people attended. £365 was raised in donations and other events have been planned for Judi's year as Master which runs until June 2020.

We are very grateful to Judi and the Portsoken Ward for choosing us as their charity. If you would like any more information about the Portsoken Ward or their future events please contact Judi at judisanders67@gmail.com

Perhaps you know of other organisations and groups that could adopt PMRGCAuk as their charity for a period of time. If so please email candy@pmrgca.org.uk if you need any help in approaching them.

ROB MURTON REMEMBERED

Rob, one of our longest serving volunteers, sadly died in August. Kate Gilbert pays tribute to the contribution he made.

Way back in 2012, when PMRGCAuk was just getting going, the organisation on a national level basically boiled down to me, as Chair of Trustees, our part time assistant Nadya and Laurene who was helping with memberships. Nadya and I spent much of our time packing and posting information packs. Then one day we heard from Rob Murton in Lincolnshire. He had GCA, and was thinking of setting up a local group. In the meantime, he asked if he could help with some admin work that he could do from

home. He generously agreed to try his hand at the information packs. I went to visit Rob and his wife at their home, and we got started. Rob never let us down, keeping the packs flowing out to new members and newly diagnosed people for more than six years and then taking on the job of sending out NewsWire three times a year. He was happy to stay in the background but his contribution to the work and the growth of the charity was immense. I'm so sorry that we have lost such a true friend and a generous spirit.



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

RESEARCH ROUND UP

At the recent Members' Day, I spoke about two recently published studies. I'm going to summarise them again here before we look at a couple of new pieces of work that I think you might find interesting.

First is the "Your Ears" study¹ that was funded by the North East Support charity that closed last year. The charity, together with researchers from Gateshead Hospital, sent questionnaires to people on their database who had GCA. It asked about symptoms relating to their ears. They sent the same questionnaires to people with PMR, to act as a control group. They found that hearing loss, tinnitus, vertigo and loss of balance were all more common in people with GCA than in people with PMR. Ear symptoms, especially hearing loss, often occurred at the same time and on the same side of the head as a GCA-headache. The ear symptoms also improved with steroid treatment. This is the first study to look at ear symptoms and it isn't perfect, but it should prompt more research into the involvement of the ear in GCA. In the meantime, we should encourage doctors to think about hearing loss

and other ear-related problems as potential symptoms of GCA.

The second study that I discussed looked at how PMR and GCA might be related to vascular conditions². We know from previous research that people with PMR and GCA are more likely to develop some other health problems, such as heart attacks. We don't know whether the PMR and GCA cause those vascular conditions, or whether something else causes the PMR and GCA and the vascular conditions. Researchers in Norwich showed that it is likely that there is a 'common cause' at work. High blood pressure was associated with going on to get PMR and previously having smoked with getting GCA. Again though, there is lots more work to do to understand this better.

In a separate study, researchers in Leeds used a very large dataset to show that there is an association between steroid dose and likelihood of an infection in people with PMR and GCA³. Doctors already suspected this, but there was previously no evidence that this was really the case for people with PMR and GCA. The authors say that it will help to guide the use of new treatments such as tocilizumab and to calculate the real economic costs of PMR and GCA. This is important if we want money for research into new treatments.

Finally, at the Members' Day, a

couple of people asked me about PMR and GCA and ethnicity. I didn't think there was any research on this, but I came across a new paper from America⁴. It looked at 573 people aged over 50 having a temporal artery biopsy. 92 had biopsy-proven GCA. From the study, the researchers concluded that GCA is more or less as common in black as in white Americans.

References

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2. Yates M et al. Cardiovascular risk factors associated with polymyalgia rheumatica and giant cell arteritis in a prospective cohort: EPIC-Norfolk Study. *Rheumatology* (Oxford). 2019 Jul 19. pii: kez289. doi: 10.1093/rheumatology/kez289. [Epub ahead of print]
3. Jianhua Wu, et al. Incidence of infections associated with oral glucocorticoid dose in people diagnosed with polymyalgia rheumatica or giant cell arteritis: a cohort study in England. *CMAJ* June 24, 2019 191 (25) E680-E688; DOI: <https://doi.org/10.1503/cmaj.190178>
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ACROSS THE COUNTRY

CHICHESTER SUPPORT GROUP

The Chichester support group meets monthly in Pagham, West Sussex and over the last few months has welcomed even more new members. We have had several successful promotion stands at local events and, at our September meeting, an informative talk on the most beneficial forms of exercise. October saw a local pharmacist come to unravel some of our drug related questions and November a herbalist came to discuss possible herbs to support our immune systems.

We look forward to 2020!

ILKLEY GROUP

At our last big meeting we were lucky enough to have Rheumatologist, Dr Colin Pease, as our guest speaker. He has been associated with the charity for many years. The meeting was run as a question and answer session. The questions were set by the group members and were submitted to Dr Pease in advance. There was also time at the end for any other queries. The meeting gave us all an insight into PMR/GCA from a consultant's perspective, how a diagnosis is arrived at and the treatment. The meeting was attended by half of our members and was extremely successful.

Since our last meeting, and due to the distances some of our members have to travel, we have decided to split into four regional groups namely: South Yorkshire; North Yorkshire; Leeds and Ilkley. The four groups collectively will be known as the 'Yorkshire' support group. Some of our members live in Lancashire – any volunteers to start a group there?!

NORTH EAST SUPPORT GROUP

We hosted our second meeting in July with 30 members attending. We were very fortunate to welcome Dr. Saravanan Vadivelu (Gateshead NHS Trust) and Dr. Sarah Mackie (Leeds NHS Trust). Both have been heavily involved with the research and consultation of PMR and GCA for over a decade. Dr. Saravanan is organising a PMRGCA education teaching programme for GPs in the North East and Dr. Mackie is assisting him.

Also at the meeting John Robson (NE Support Group Organiser) delivered a humorous and thought-provoking presentation of the "A - Z of living with PMR in remission".

TAUNTON GROUP

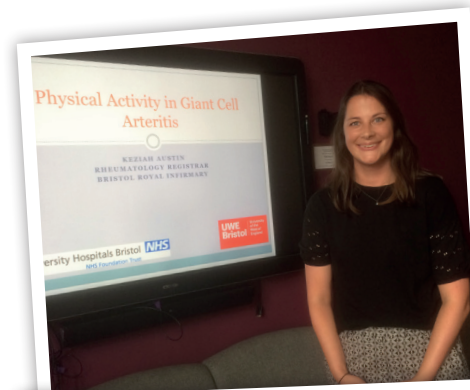
At our July meeting, Dr Keziah Austin, from the Rheumatology department at Bristol Royal Infirmary, talked to us about her investigations into the effects of exercise on patients with GCA and PMR.

She explained that exercise is therapeutic as it has an anti-inflammatory effect but unfortunately both the symptoms and the treatment of our conditions can impact on our ability to exercise.

Her project involved interviewing 36 volunteers with GCA/PMR about their attitudes to exercise.

Barriers to physical activity included fatigue, pain, stiffness and weakness, as well as side-effects of steroid medication, lack of confidence and fear of falling.

Motivation was viewed as a key factor in encouraging the volunteers to take more exercise as well as easy access to facilities and personalised strategies led by professionals. A



Dr Keziah Austin at Taunton Group meeting

recent study in Bristol showed that an hour's Nordic walking resulted in an improvement in fatigue and increased emotional wellbeing. Pilates and Tai Chi are also appropriate forms of exercise.

Many thanks to Kez for her very interesting and informative talk. Several of our members are now looking at taking up Nordic walking!

WHITSTABLE MEET UP GROUP

We had our first meeting in June in the District and Women's Institute Building in Seasalter. The meeting was attended by our Group Organiser Tom Withers, 20 attendees plus Penny Denby, Trustee. We meet monthly and have decided to move to the Riverside Church which has a nice café and a separate quiet area.

FIRST SOUTH WEST GROUP LEADERS' MEETING

In July, group leaders and volunteers from Taunton, Truro, Plymouth, Stroud and Bath met up in Taunton for the first regional group leaders' meeting.

It was an opportunity for everyone to put forward points for the group to discuss and also share ideas and tips, which was particularly beneficial for new leaders. Wendy Morrison (trustee and group leader, Taunton) talked about some of the national charity issues and how regionally we can help. Everyone agreed that it was a great opportunity to be able to meet up and hopefully we will have the opportunity to do this again.

Fundraising ideas for December and beyond

It is vital that we increase our fundraising to ensure that our charity remains sustainable for ourselves and those that come after us.

Many of you kindly donate, for which we are always grateful. Here are a couple of additional ideas for December and beyond.

SAVE AS YOU SHOP

If you internet shop, you could donate to PMRGCAuk without spending any more money.

Log on to: www.giveasyoulive.com (GAYL), choose PMRGCAuk as your charity, sign up for free and shop! It's really simple. GAYL works in association with many familiar shops such as Amazon, John Lewis, Argos and Trainline. Contact us if you need any help with setting this up.

Ask your friends, family, co-workers, employers if they can sign up and nominate us too - one member has raised £10 over the year for us and a business has raised £800.

CHRISTMAS CARD STAMPS

Remember to save all your stamps from Christmas cards or other post, from the UK or abroad, and send to: PMRGCAuk Stamp Appeal, 10 Chestnut Ave, North Walsham, Norfolk, NR28 9XH. Please trim to within 1cm of the stamp but not so close that you damage the perforations.



SPONSOR JOHN ROBSON'S CLIMB OF MOUNT ANNAPURNA IV IN THE HIMALAYAS

We are pleased to hear that John Robson, North East Group Organiser, safely descended from Mount Annapurna at the end of October. He climbed around 7,500 metres of one of the coldest, remotest and most dangerous mountains in the world. Due to an avalanche risk he had to turn back on his final quest to reach the summit. We are so pleased he is safe and are in awe of his achievement. He is raising funds for us and can still be sponsored at <https://uk.virginmoneygiving.com/fundraiser-display/showROFundraiserPage?pageld=1090282> or you can send a cheque to BM PMRGCAuk, London, WC1N 3XX

CAN YOU HELP?

As a small charity we rely heavily on the support of many volunteers. We are specifically looking for people to help with the positions below but if you have any time or skill that you could offer, please let us know.

Would you like to help organise our Central London group? We meet three or four times a year between Liverpool Street and Aldgate stations on a Monday lunchtime. We usually have an

expert speaker followed by questions and discussions with drinks. We attract people from across London.

We're also looking for someone to help mail out NewsWire three times a year. It would involve preparing the envelopes for posting and getting them to the post office.

Email info@pmrgca.org.uk if you can help at all.

Members' I

The sun shone again on what turned c

The AGM was chaired by Humphrey Hodgson - chair of trustees - who talked about the achievements of the past year and our goals.

The charity has grown its membership: individual memberships are up by 9% and we have increased the number of groups around the country and now have 37. There is a bias towards the south still and it is our ambition to develop more in the north.

PMRGCA North East, a separate charity, merged with PMRGCAuk during the year. Assets of the former charity were transferred to PMRGCAuk and used to fund education of GPs in a regional project along with some research into GCA and hearing loss (see Research Roundup on page 3 for more information).

Humphrey explained our vision of a future where everyone affected by PMR or GCA receives fast, effective treatment and enjoys the best possible quality of life. We aim to do this by increasing awareness of symptoms, diagnosis and treatment to patients, carers and health professionals; campaigning for fast track diagnosis of GCA; and being involved in research. He also highlighted the need to raise funds to ensure our sustainability.

Before the AGM was brought to a close, the members accepted the amendment to the Memorandum of Association of PMRGCAuk, the treasurer's report and the re-appointment of all trustees.

We were very fortunate to have four inspirational speakers. First, Dr. Sara Muller, Trustee and Research Fellow at Keele University. Sara talked about two pieces of research: The "Your Ears" study looking at a connection between GCA and the

auditory nerve and one looking at the cardiovascular risks associated with PMR and GCA. (Both of these are covered in her Research Roundup on page 3.)

Finally, Sara talked about an ongoing study into pain and stiffness in PMR which she has taken over with new funding from Versus Arthritis. She mentioned that she would be looking for more patient input. (Update: Sara posted details on HealthUnlocked in October and now has enough people for the study.)

After lunch, Rheumatology Consultant Chetan Mukhtyar from Norfolk and Norwich University Hospital laid out the significant improvements in diagnosis and treatment of GCA that a committed and knowledgeable consultant can achieve. (A report of his presentation can be found on page 8.)

Dorothy Bryne, trustee and deputy chair of PMRGCAuk, highlighted the difficulties patients can experience in getting a diagnosis for PMR or GCA and talked about her journey from first symptoms through to diagnosis, remission and relapse. (See page 9 for her account.)

Lastly, member Eileen Allcock, inspired us all with her presentation about her sponsored row from Birmingham to Worcester which took place in May. We wrote about her challenge in the spring edition of NewsWire before it had taken place and she was here to tell us how it went.

She admitted that she didn't know whether she would be able to do it or not. But with the help of her husband, Ken, she paddled her way along 30 miles of canal through tunnels and locks over three days. She was interviewed for local radio, received



Day & AGM 2019

d out to be an informative and inspiring Members' Day.



Eileen Allcock, inspired us all with her presentation about her sponsored row

help from strangers and raised several hundred pounds for the charity.

"I'm so glad I did it," she said and encouraged everyone to help raise funds in whatever way they could. "You might feel like a very small fish, but that doesn't matter and you never know where it will take you."

There was time for questions and answers built into every session and the afternoon wrapped up with the chance to chat with the speakers.

RECYCLED GREETING CARDS AND RAFFLE RAISE £300!

The annual raffle and sales table was organised by Kent Groups. Christine Wallace, Membership Secretary for Orpington, ran the sales table. Prizes for the raffle were donated by Kent members and the PMRGCAuk events committee. Handmade items were generously made and donated by members in Maidstone and Orpington groups.

Thank you to them all and to trustee, Wendy Morrison, who asked, "Can I help?" and then sold raffle tickets to all present.



Special thanks go to:

All our members who brought old greetings cards to the AGM. They will be recycled into new cards as soon as possible. If you would like to sell some of the cards we make at your support group please email penelope@pmrgca.org.uk We won't post them to you because of the cost but wherever possible if a member of the PMRGCAuk team is coming to your area we will do our best to arrange to drop some off!

The five members of PMRGCAuk events committee who took on catering for this year's Members' Day, particularly – Debbie Pitt, Oxted Meet Up Organiser and Sandra Watson, Volunteer. They served up an excellent lunch as well as light refreshments during the day. And thank you to member Lesley Bennett who drove two committee members from Kent to London with food and provisions in her black cab early on Saturday morning.

And of course, to everyone who attended the event; our speakers and all the other volunteers who helped make the day run smoothly.

It was great to...

"meet a group of people suffering from the same conditions as me and be able to chat to them about their experiences..."

"meet the professionals and ask them questions...their presentations were interesting and entertaining..."

I'm leaving feeling...

"inspired to do my bit to help others and PMRGCAuk."

"keen to join my nearest support group based on today's experience."



MICROPHONE PROBLEMS

We are aware that some attendees found it difficult to hear some of the speakers during the day. Those of you that arrived early will know that we had problems setting up the microphone and had to take the decision to run without it. We apologise for this and will make sure next year to source a microphone that works properly.



GCA AND THE NORWICH APPROACH

A report on the presentation given by Dr Chetan Mukhtyar at Members' Day 2019

Dr Mukhtyar started out as a consultant in 2009 with an impressive academic background, having published a major paper on the treatment of GCA, but he told the meeting with refreshing honesty, 'I realised this did not necessarily translate to better healthcare for the patient.' At several points, the system could fail. Many patients were not referred to the hospital unless their condition was 'refractory' – meaning that their GCA was hard to manage, often because it didn't respond well to the dose of steroids used. Referrals by GPs could be treated as routine so they could take months and they might go to a wide variety of specialties, some not necessarily appropriate. The dosage of prednisolone could be anything from 10mg to 100mg. Methotrexate was given sometimes but the reasons for it to be prescribed were not clear and the doses given could be very different. Patients did not always get biopsies and, when they were given, they might be carried out by different departments. A biopsy might happen quickly or take two or three weeks depending on the availability of theatre slots and there were inevitable delays in receiving reports. Some patients couldn't access hospital treatment at all and there was no sense that patients needed to be empowered; they had no means of controlling the dose of steroids they were taking. As access to healthcare in general was so difficult, some patients often stayed on too high a dose of steroids for a long period. Some people didn't have proper hospital follow-up and monitoring for complications and relapses was unsatisfactory.

Now things are much improved. With the help of his colleagues in ophthalmology, especially Consultant Ophthalmologist, Mr Colin Jones, there is an agreed pathway for the patient journey, investigative protocols and drug management. Every fortnight there is a dedicated GCA clinic and every week there are six dedicated fast-track slots for ultrasound of suspected GCA. In 2012 there were only 19 referrals to that clinic and now there are 120-150 new referrals a year. All patients with visual symptoms go directly to ophthalmology and those with no visual symptoms go straight to rheumatology. Everyone is checked to ensure the cause of their symptoms is not cancer. Everyone goes on a high dose of steroids urgently. They have developed an evidence-based regimen for prednisolone (The Norwich Regimen <https://academic.oup.com/rheumap/article/3/1/rkz001/5305663>) which has become the standard of care in Norwich. The prednisolone regimen lasts for 100 weeks. It delivers prednisolone tailored to height, weight and gender of the patient. 100 patients have now completed the 100-week regimen and a subsequent 50-week observation period to ensure that they are not relapsing. 71 of the 100 patients have been off steroids and sustaining remission at 150 weeks.

These are unpublished results and therefore need to be treated with cautious optimism. Dr Mukhtyar is in the process of analysing the side effect profile of this regimen.

Dr Mukhtyar went to Norway to learn more about using ultrasound as an alternative to surgical biopsy

as a diagnostic technique. As part of a quality control exercise, he looked at his first 25 cases and compared them to the results of the biopsy, and physician verified diagnosis at 100-week follow-up. Although there was a modest correlation with biopsy at the beginning, there was an excellent correlation of ultrasound results with final diagnosis at 100 weeks and in fact, biopsy was less reliable than ultrasound. So at the Norfolk and Norwich University hospital, they scan all patients using ultrasonography and biopsies are only offered to patients with a negative scan. This had the added advantages of being more cost-effective, easier to perform, faster to get a diagnosis and less invasive.

Dr Mukhtyar and his colleagues effectively developed their own standards of care for GCA. Their aim is to see patients with suspected GCA on the same day and to give them immediate high dose steroids. The aim is then to scan patients within seven days and if necessary, biopsy within four weeks and to follow up patients until steroids are stopped. Any suspicion of a relapse is diagnosed objectively. All relapses are then treated to protocol with escalation of prednisolone and addition of either methotrexate or tocilizumab.

New national guidelines are soon to be introduced and they may in some ways differ from the guidelines which Norwich has developed. But the most important point, says Dr Mukhtyar, is to have a fast track system and effective long-term follow-up. He is a co-author on the recent update of the European recommendations for managing large vessel vasculitis (<http://dx.doi.org/10.1136/annrheumdis-2019-215672>) and also on the soon to be released British recommendations for GCA. But he says that we need to learn lessons from the National Early Arthritis Audit which has influenced a change in practice in the UK. However, for something like that to happen, the first step needs to be to develop standards of care for patients with GCA.



THINGS CAN ONLY GET BETTER!

Dorothy Byrne's talk at Members' Day was a reflection on her experiences of PMR and GCA and of being a trustee, how far we've come and how much there is still to do. Here, she summarises what she said.

Knowledge among the public and medical profession about PMR and GCA has improved over the past decade and so have diagnosis and treatment but there is still a long way to go. And our charity will play a key role in finding the way forward.

That's my view, based on my experience of developing both conditions ten years ago and having a relapse recently, alongside being a trustee of the charity throughout the intervening period.

I was a 'young sufferer' when I developed PMR at the age of 57. My GP put me on a relatively low dose of prednisolone but my symptoms grew worse and worse and, despite the fact my CRP rose to 81 and I moved with great pain and difficulty, the dose was increased to only 20mg. Finally, I developed symptoms of GCA but the GP said I needed to see an Ear, Nose and Throat specialist. I told her the symptoms were those of GCA and that I needed to go on to 60mg of steroids at once and see a rheumatologist. She said she didn't really know what to do. Luckily, I rang a relative who is a doctor who told me I should take 60mg at once and I got a referral to the right person and the correct treatment. I recovered in just over three years. And I sent a stiff letter to my GP's surgery saying they needed to get up to speed!

Over the years, writing articles

for the charity, I have heard deeply distressing stories of women and men being fobbed off by doctors as suffering just the normal aches and pains of old age when they developed PMR and losing some sight or even going completely blind with GCA.

But my sense is that the public and doctors are more aware of the conditions than they used to be. Also, our conditions, in my view, were not seen as being that interesting because they affected older people who were, on the whole, just put on steroids. Now drug companies and researchers are much more interested in us - I think the pharmaceutical industry realises there are many thousands of us so there is money to be made developing new drugs.

I broke my arm early this year which appears to have been the trigger for a relapse of both conditions. I am now on one of the new biologic drugs, Tocilizumab, which means I can come off steroids. Our charity campaigned for that drug to be made available and appealed successfully when NICE at first declined to approve it. So I am a direct beneficiary of the good work we do. Currently it's only available for people with relapsing and recurrent forms of GCA but I hope that over time most people with our conditions will have access to these new sorts of drugs so that being on steroids for years on

end will be a thing of the past.

Biologics for both conditions are being developed and tested. I am sure our charity will play a vital role in campaigning for them to be made available. We deserve expensive drugs just as much as younger people do.

I have been a representative of the charity on the international committee drawing up new guidelines for the diagnosis and treatment of GCA. These should be introduced in the next few months. They make clear that there should be a fast track system for people with GCA as there is for people with strokes. Nobody should ever lose sight because of a delay in treatment. When the guidelines are introduced, our charity must campaign alongside others for them to be put into practice across the country. We hope to create an information sheet that members can use to campaign to get good treatment in their areas.

Over the years I have seen so many people helped by being in groups. I'm in the London group which meets near Liverpool Street Station and it means so much to me to meet others with the conditions. We need to develop more groups and somehow persuade doctors' surgeries and relevant hospital departments, especially rheumatologists, to tell patients about us

There is so much happening that is exciting and so much call on our resources with a tiny part-time staff that we need urgently to think of new ways of fundraising. So, if you have any ideas, do tell us!



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 candy@pmrgca.org.uk

FROM SIGHT LOSS TO NEW ZEALAND

Sue Chandler (aka DorsetLady on HealthUnlocked forum), 72, shares her experience with us.

My journey began in 2010 with muscular pains in my shoulders and upper arms.

I was diagnosed with a frozen shoulder and referred to a physiotherapist. The treatment wasn't successful so over the next 15 months I received three cortisone injections which gave little relief. Then when the pain moved to the nape of my neck and head (including tender scalp, jaw claudication, although no enlarged nor tender temporal artery) I was prescribed Amitriptyline for suspected trapped nerve from a frozen shoulder but again this didn't help.

In April 2012 the vision in my right eye began to blur. I asked my GP if there was any connection between all my symptoms and was told no! Over three days my eye deteriorated until I had no vision in it at all. I went to A&E and was immediately diagnosed with GCA and started on 80mg Prednisolone and had to wait two weeks to make sure the other eye was unaffected.

I had never heard of GCA and couldn't believe it had taken 19 months to be diagnosed. I was very upset to lose the sight in one eye and distraught that I might lose the other one too although relieved when I was finally given the all clear.

I've had to adapt to only being able to see with one eye. Watching television, navigating around people, up and down steps, pouring a cup of tea: all these things, and more, are possible but have taken time to adjust to.

One of the side effects of Prednisolone was an induced cataract which proved a bit difficult for a while. I had adapted to driving again since partially losing my sight but with the rapid development of the cataract it got to the point where I was almost unable to drive. I pushed hard to get the surgery sooner than the surgeon would have liked and just a few months later I flew to New Zealand to spend Christmas with my daughter and family. I was down to 7mg by then and I realised that despite having GCA and being mono-sighted it wasn't going to stop me doing what I wanted to do. (And in fact I returned

to New Zealand in 2017 and I intend to go again in 2020.)

The rest of my GCA journey was relatively straightforward. I saw the rheumatologist only twice, both in the first year after diagnosis, and was told my GP could manage my GCA. They have let me reduce at my own pace, depending on lack of symptoms and corresponding ESR readings. There was one hiccup when my stress levels were very high, when my late husband was diagnosed with terminal liver cancer. My ESR was high, although there was no GCA flare.

I reduced to zero in September 2016.

My children, grandchildren and my sense of humour have helped get me through it all. Fortunately, I also found PMRGCAuk about six months into my treatment. Shortly after that I joined the HealthUnlocked forum (I'm Dorsetlady) and I'm also a member of a local support group. They really helped me to get through the bewilderment of my early days and as I learned more about my illness, I have tried to pass that information on to new patients.

HELPLINE UPDATE

We are delighted that, in response to our appeal at the AGM, Sheena Turner has joined our team of Helpline volunteers. Sheena has previous helpline experience but has chosen to update this by attending a training course on "Essential Helpline Skills" run by the Helplines Partnership, of which we are a member.

Although this brings the Helpline team up to strength, we are always happy to consider any member who thinks they could help others by listening sympathetically and providing information – never advice – so no need to be an expert!

NEWSFLASH FROM ABERDEEN

Great news! The newly formed Aberdeen group has found a venue for their next meeting, to be held from 1.30pm to 3.30pm on Thursday, 17th October. Thanks are due to David Carrott and Janette Glass for organising this.

The group will meet in the Morven Room at the Hub, Cults Kirk Centre, 404 North Deeside Road, Cults, AB15 9TD.

There is a table reserved from 12.30pm for those who wish to have lunch, or a snack and the cafe serves teas, coffees, soup, sandwiches and cakes, all home-made.

The number 19 bus from the city centre will take you nearly to the door or, for anyone coming by car, it is close to the new bypass.

There will be no charge for the meeting but items from the cafe must be paid for.

All interested are welcome, members new and old (sorry, not old; existing would be a better word), family and friends. No need to book a place; just turn up.

For more information email aberdeen@pmrgcascotland.com or ring 0300 777 5090 and ask for a message to be passed to one of the trustees.

WEBSITE UPGRADE

As you know, anything to do with technology moves at a rapid pace so the trustees started a project in 2018 to review and improve our website. A number of improvements were identified: better software to manage the information, brightening its appearance by enabling easier addition of images and colour, increasing the security of traffic to and from the site and changing the web address to reflect that we are a Scottish charity.

We are very grateful to a student from Dundee University who has assisted and guided us in this process. While yet to be completed, the new website (www.pmrgcascotland.com) is now up and running, although the old one will remain available for some time to redirect traffic to the new site.

This was a major project as not only the new website must be built but new email addresses must be created, Facebook and Twitter accounts must be changed and all the cloud storage must be transferred. Most of this is now in place so the new addresses to contact the Charity have become:

chair@pmrgcascotland.com
(replacing info.scotland@pmrandgca.org.uk)
secretary@pmrgcascotland.com
edinburgh@pmrgcascotland.com etc.

All the old email addresses still work and will do so for some time.

The next step involves altering all the documentation – trifold leaflets, membership cards etc. We shall amend these when we reorder them.

Finally, and most importantly, would you all please keep an eye on the new website and let us know if you spot any spelling mistakes or have any suggestions for improvements or additions. Send us "Hints and Tips", new "Our Stories" or relevant photographs. As with all things to do with PMRGCA Scotland we want the website to reflect the interests and wishes of our members.
Michael Benneworth, Secretary.

(Chair's comment: I can't thank Michael enough for the work he has put into this task. There has been input from others but essentially it has been a one-man job. We are lucky there was a man willing to take it on, along with everything else he does on behalf of the charity. Thanks a million from all of us.)



HELPLINE

0300 777 5090

www.pmrgcascotland.com

Registered Scottish Charity No
SC037780

Registered address
7 Hamilton Place, PERTH, PH1 1BB



SUPPORT GROUP AND MEET UP CONTACTS

Our network of groups around the country is growing! Scotland is an independent organisation.

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.

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

NORTHERN IRELAND

LISBURN MEET UP

Contact: Caroline Stewart
pmrgca.ireland@gmail.com

SCOTLAND

PMR-GCA SCOTLAND

Contact: Lorna Neill (Chair)
www.pmrscotland.com
chair@pmrgcascotland.com
Tel: 0300 777 5090

WALES

CARDIFF SUPPORT GROUP

Contact: Sue
cardiff@pmrgca.org.uk

NORTH EAST ENGLAND

NORTH EAST MEET UP

Contact: John Robson
northeast@pmrgca.org.uk

NORTH WEST ENGLAND

YORKSHIRE MEET UPS (ILKLEY, LEEDS, SOUTH YORKS AND NORTH YORKS)

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: Karen
bedfordshire@pmrgca.org.uk

CAMBRIDGE MEET UP

Contact: Trisha
cambridge@pmrgca.org.uk

EAST ANGLIA SUPPORT GROUP

Contact: Sandra Waspe
pmrgcaeachair@btinternet.com

HARLOW MEET UP

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

SOUTHEND/CHELMSFORD SUPPORT GROUP

Contact: Pat Fedi
southend@pmrgca.org.uk

WELWYN GARDEN CITY MEET UP

Contact: Sheila
wgc@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

EAST DORSET MEET UP

Contact: Pat Worthington
eastdorset@pmrgca.org.uk

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

TRURO MEET UP

Contact: Margaret
truro@pmrgca.org.uk

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
orpington@pmrgca.org.uk

SOUTH AND SOUTH EAST ENGLAND

BRIGHTON MEET UP

Contact: Catherine Spencer
brighton@pmrgca.org.uk

CHICHESTER SUPPORT GROUP

Contact: Patricia Dawson
chichester@pmrgca.org.uk

EASTBOURNE MEET UP

Contact: Janet
eastbourne@pmrgca.org.uk

MAIDSTONE SUPPORT GROUP

Contact: Margaret Hicks
maidstone@pmrgca.org.uk

OXTED MEET UP

Contact: Debbie Pitt
pmrgca.oxted@gmail.com

PORT SOLENT MEET UP

pmrgca.portsolent@gmail.com

SURREY SUPPORT GROUP

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

WHITSTABLE MEET UP GROUP

Contact: Tom Withers
whitstable@pmrgca.org.uk

WORTHING SUPPORT GROUP

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