PMRGCAUK
NewsWire
ISSUE 12: SUMMER 2014

INSIDE THIS ISSUE

NATIONAL HELP LINE
0300 111 5090

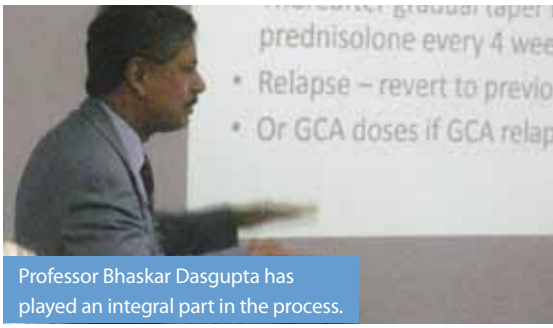
PMRGCAUK is a registered charity established to meet the needs of people with these debilitating conditions by raising awareness, promoting research and offering support.

PROGRESS UPDATE:
Developing PMR Guidelines

Previously we mentioned work being done by the working group set up by EULAR (the European League Against Rheumatism) and the ACR (the American College of Rheumatology), to establish an international set of guidelines for the management of polymyalgia rheumatic cases. This is the first time that such an international project has been attempted for PMR, drawing together and sharing knowledge and experience of experts all over Europe and the United States. We are delighted to report that the group is very close to submitting its final official report. As several patient representatives have been involved right through the process, we have had advance sight of the report.

The success of the project has been recognised by EULAR - a considerable achievement, highlighted at our recent AGM and Members' Day by Honorary President, Professor Bhaskar Dasgupta (pictured), who has played an integral part in the process.

The working group restricted its focus to cases of PMR without accompanying GCA. Even so, it was a massive undertaking.



Professor Bhaskar Dasgupta has played an integral part in the process.

Recommendations have to be based on best available research evidence. Only studies using original data were included each one being evaluated on the strength of the evidence for its findings and conclusions.

Being involved in this exercise demonstrated to us patient representatives how so much of the research into PMR is scientifically of poor quality because the criteria for first-class clinical research, i.e. double-blinded studies, are not

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FEATURED FUND RAISER: JACQUIE SMALL

Our thoughts were with Jacquie as she joined over 1,000 others taking on the Grand Union Challenge on 28th – 29th June. Challengers walk, run and even paddle board on the Grand Union Canal towpath, from the heart of London towards the Chilterns. Read more about her story on p.5.

Lord Butler

It was great to catch up with our patron at the House of Lords in April. Lord Robin Butler is one of the few people in public life willing to speak about his personal experience of PMR – something that we hope will encourage others to do the same. Lord Butler is taking an active interest in the charity, which includes giving a talk which shares his experience of serving five prime ministers at an upcoming event for PMRGCAUK – watch this space for more information.

Developing PMR Guidelines: from page 1>

being met. Researchers are using patients' data, but large-scale trials are not being done. As previously noted this is because pharmaceutical companies, who fund so much clinical research, are not interested in PMR. Why not? Because glucocorticosteroids work, and they are cheap.

Recognising steroids are effective in the vast majority of cases has not deterred experts from wanting to reduce the total amount of steroid taken by a PMR patients during their illness in order to avoid "relapses" and that pattern of reducing the dose too far and too fast, only to have to raise it again. The rheumatologists on the working group were unanimous in seeking to mitigate the effects of long-term steroid treatment. This led to them recommending initial dosage should be as low as possible within the range 12.5 to 25mg daily. It was surprising to learn that in Germany, it is common to start people on 25mg a day! There was discussion about patient body weight and whether smaller people should be started off on a smaller dose. But again, the issue of quality of evidence has meant that this would not be conclusive.

> **' It mustn't be allowed to become mere tokenism which means that we need to grasp every opportunity to become involved'**

The experience was valuable for patient representatives. Lorna Neill, of PMR-GCA Scotland, says how important it is for patients to continue to be involved in research.

' It mustn't be allowed to become mere tokenism,' says Lorna, 'which means that we need to grasp every opportunity to become involved and to contribute wherever we are given the chance. If we don't say what is important to patients how will EULAR ever know?'

We were keen to make sure that any studies showing effects of non-medical treatments, such as herbal remedies or physiotherapy, should be included in the work of the group. As we expected, the literature review did not reveal any high quality studies about the benefits of diet, exercise, or non-drug therapies on cases of PMR. However, all members of the working group agreed that it would be great to have more knowledge, and evidence, about these supplements to drug therapy.

When the report of the working group is officially published, we'll provide more details of its conclusions and recommendations.

DIET AND NUTRITION:

Ask the dietician!

Elizabeth Bowey answers some useful dietary questions

As registered dieticians we work to 'Evidence-Based Practice' where we will only recommend specific dietary changes where there is evidence (clinical trial results) to show that these changes will have a beneficial effect. When there have been no clinical trials on a particular dietary item or specific nutritional supplements/ herbal remedies then it is up to the individual to make their own choices and to discuss this further with their medical or pharmacy team.

The cause of PMR/GCA is unknown and there have been no specific clinical trials looking at diet and PMR/GCA. However, the inflammatory processes of these diseases are well understood, and the effects of diet and inflammation have been well studied.

Key Points:

- Changing your diet will probably not have such an impact on your symptoms as your medication, so always consult your doctor or pharmacist before making any changes to your medication
- A healthy balanced diet can help prevent potential side effects from medications. Eg. osteoporosis and weight gain from steroids
- An anti-inflammatory, healthy (Mediterranean-type) diet can also help to protect against heart disease and certain cancers so is suitable for the whole family

Anti-inflammatory Diet Principles (Mediterranean-type diet:)

- Include omega-3 oils from oily fish
- Healthy oils and fats (olive, rapeseed, high oleic safflower and sunflower oils and margarines
- Low glycaemic index foods
- Plenty of multi-coloured fruit, vegetables and salad items

The dietary advice provided is for general use only and not for specific additional medical problems. Ask your GP for a referral to a registered dietician for more detailed dietary advice.

DIET AND PMR/GCA

Q **Is there any evidence that having a vegetarian diet means you are more/ less likely to develop PMR?**

A There is no evidence at present. There is also a lot of variation around the term 'vegetarian' as this diet can include eggs/dairy/ fish. Vegetarian diets can also be unhealthy if meats are avoided but there is no increased intake of healthy cereals, pulses, fruit and vegetables.

Q **Does VSL3 probiotic help?**

A There is no evidence at present that this probiotic is useful for PMR/GCA. Most research has been directed at problems within the gastrointestinal and respiratory tract.

Q **Are there any food which are bad for PMR, such as tomatoes or acidic foods?**

A Unless you have a medically-diagnosed food allergy or problems with acid reflux/ indigestion related to specific food items, there is no evidence to suggest any benefit from avoiding any particular food items

DIET AND PREDNISOLONE

Q **Is there any way of getting enough calcium/fit D in the diet to maintain bone density without having to take the alendronic acid medication?**

A This depends on the risks of fracture for each individual and should be discussed with the GP. All risk factors would need to be considered as well as steroid use. National Osteoporosis guidelines state that "Individuals at high risk, for example those aged 65 years or over and those with a prior fragility fracture, should be advised to commence bone-protective therapy at the time of starting glucocorticoids . Measurement of bone density is not required before starting treatment."

Other individuals may be referred for a DEXA scan to assess risk but everyone should be advised on good nutrition, an adequate dietary calcium intake and appropriate physical activity should be encouraged, and tobacco use and

alcohol abuse avoided.

Medicines such as alendronic acid are considered to be "bone-protective" whilst calcium and vitamin D is considered an adjunct to treatment (added on).

Arthritis UK recommends 1000mg of calcium each day. This can be easily be achieved by including several portions of low fat dairy products, canned fish with bones (sardines) or fortified breakfast cereals.

Vitamin D is not so easy to source from the diet which is why exposure of skin to sunlight and vitamin D supplements are important. Vitamin D is present in some oily fish, fish oils, margarine and some fortified breakfast cereals and dairy products.

Q Is there any food that one should or shouldn't eat near to taking prednisolone? Would drinking white (dry) wine , the odd glass at social events, upset the 'preds'?

A Prednisolone should preferably be taken in the morning after breakfast. By taking after food, the risk of gastrointestinal side effects is reduced. Side effects such as heartburn and indigestion may occur whilst taking prednisolone so it is important to avoid other foods and medicines that may also cause these problems for example spicy foods, caffeine containing drinks and alcohol. However, the odd glass of wine or a curry is not going to cause long-term problems. Your GP may prescribe a medicine to protect your stomach, for example omeprazole, particularly if you are taking other medicines such as non-steroidal anti-inflammatory drugs (ibuprofen, naproxen, diclofenac etc) for your condition or aspirin or if you have had a previous stomach ulcer.

There is no evidence that using enteric coated prednisolone is of any benefit compared to standard tablets.

Q Can you give some general advice about vitamin supplements, I know that some are not advised with prednisolone.

A Unless you have been prescribed vitamin and mineral supplements by your medical teams you should be able to obtain adequate levels from a healthy balanced diet and safe exposure of skin to sunshine. Any concerns about medication should be discussed with a pharmacist.

Q One of my first symptoms was weight loss and I have struggled ever since to maintain my weight. It took me about 18m after starting prednisolone to gain half a stone and just weeks ago I lost this within a week. Are there any nutritional tips to deal with this?

A Most people find it easiest to increase the fat content, or traditional treats such as cakes ,biscuits and puddings, in their diet in order to increase their calorie intake. High- fat dairy products such as full- fat yoghurts, cheese and butter are usually popular and palatable, but if you prefer to include healthier fats and oils try including more oily fish, avocados, nuts, hummus and olive oil. If you are still struggling to increase your weight, discuss this further with your GP and ask to be referred to a dietitian.

Q Despite low weight and a very health diet I have high cholesterol – advice please?

A There are several reason why cholesterol levels in the blood may be high, including genetics. This should be discussed initially with your GP. Keeping a healthy weight and taking a healthy diet low in saturated and trans fats are both important. Additional dietary changes such as taking foods high in soluble fibre such as oats, soya, pulses and cholesterol-lowering products containing plant sterols and stanols can reduce cholesterol levels by about 15 %.

Q I am terribly tired and it takes me ages to really get going in the morning and I have permanent tendonitis in my elbow, but I gather from Kate Gilbert's excellent book that these can be the side effects from long term steroid use - are there any foods which help?

A A healthy, balanced Mediterranean –type diet with plenty of fruit, vegetables and starchy carbohydrates is the best approach. 'Little and often' meals and healthy snacks across the day. Also remember to keep well- hydrated (8-10 drinks each day)

PMR/GCA AND DIABETES

Q I am 'recovering' from GCA - currently into year 3 of treatment. I am currently on a 'maintenance' steroid dose of 2mg daily. I am now also a border line Type 2 diabetic but my GP does not know if this is aside effect of the steroids, was on 60 mg. a day at first, or if I would have developed it anyway - I'm now 67 years old. However my diabetes is being controlled by diet and I don't take any medication. Also taking a statin and Alendronic acid. Could you ask the dietician if there are any foods which might help as a detox or counter to all these horrible chemicals which my poor body has been subjected to for such a long time?

A We don't really use the term 'Detox' in dietetics as there is no evidence that toxins build up in our bodies to any significant level. For Type 2 diabetes, weight management is very

important, with an aim of keeping weight within the healthy weight range. I suggest you follow the healthy Mediterranean-type diet with a special emphasis on multi-coloured fruit, vegetables and salad items that contain lots of antioxidants and protective plant chemicals.

Q I suffer from PMR & Type 2 Diabetes (Well controlled. Metformin + close attention to diet). Are there any dietary 'conflicts of interest' between these two conditions? (My diet is guided by Diabetes, not PMR).

A A healthy Mediterranean-type diet is also a good choice for people with diabetes. However, with diabetes, as I'm sure you know, it is important to monitor your carbohydrate portions including starchy carbohydrate. Do consult a diabetes specialist dietician if you require any further specialist advice

What fruit in particular - I eat a lot of fresh fruit - is bad for diabetes. I know that eating unripe bananas is best and fresh pineapple is not very good for us.

Fruit is a very useful addition to the diet, providing fibre and useful antioxidant vitamins and protective plant chemicals. We recommend that you eat the fruit you enjoy, but limit your portion sizes (1 handful is a rough estimate of a portion), and limit to approximately 3 portions a day spread across the day. Some people with diabetes prefer to avoid certain fruit, for example mangoes, as it can leads to a raised blood sugar in some individuals

USEFUL RESOURCES

British Dietetic Association (Food Facts)
www.bda.uk.com

Arthritis Research UK
www.arthritisresearchuk.org

Diabetes UK
www.diabetes.org.uk

Elizabeth Bowey PhD RD
Community Dietitian, St Peter's Hospital, Chertsey, Surrey KT16 0PZ

RESEARCH UPDATE

Update on research in PMR and GCA

by Sarah Mackie, University of Leeds

Lots seems to be happening in UK PMR and GCA research! **Prof Raashid Luqmani**'s HTA-funded trial of vascular ultrasound for GCA diagnosis, **TABUL**, is now fully-recruited. Also nearing completion is the UKIVAS collaboration's ambitious study **DCVAS**, which aims to generate useful diagnostic and classification criteria for vasculitis (including GCA). In Sheffield, **Dr Helen Twohig** has now completed her in-depth interviews with patients with PMR to help her develop a new questionnaire to assess how PMR affects patients' lives. Meanwhile, **Dr Toby Helliwell** at Keele is conducting GP interviews to find how they deal with the challenges of managing PMR in everyday practice. Keele University is also co-ordinating **The PMR Study**, led by **Prof Christian Mallen** and **Dr Sara Muller**, in which patients with PMR are followed up for 2 years. Here in Leeds we're co-ordinating the **UK GCA Consortium study**, looking at the genetics of GCA and PMR, and our new study **ADDRESS-PMR** which is looking at the diagnostic value of ultrasound in patients with suspected PMR.

This list isn't comprehensive and is based on publicly-available information on the UKCRN Portfolio website – which is a good way of keeping up with the progress of the various studies that are out there, especially those funded by charities or the taxpayer. Drug studies are not always listed on the Portfolio site, but honourable mention must go to **GiACTA**, which is a huge international effort to find out whether a weekly injection of tocilizumab can help patients with GCA reduce and stop their steroids sooner. Exciting times – watch this space!

SPECIAL REPORT

AGM and Members' Day 2014

While our local groups meet up and get to know each other in person, we usually rely on phone calls, e-mails, the online forum and letters. The event was a great opportunity for people to put faces to names, share experiences and find out more. It was also good to meet up again with our Scotland and North East associate charity representatives.

The day began with an inspiring presentation on the development of guidelines for case management of PMR by Professor Bhaskar Dasgupta, a tireless campaigner for better understanding and treatment of PMR and GCA. This concluded with a Q and A session covering a wide range of topics, from steroid side effects to research into the genetic nature of the illness.

At the AGM we were sorry to hear that Robin Hamilton will be retiring as Chair, due to ill health. In his short time as Chair Robin his energy and commitment have had a huge impact. Thankfully, Robin remains on the Board and is still very much a part of the charity. The role has been taken up by Dr Kate Gilbert, whose previous stint as Chair was instrumental in developing the Charity to where it is today. We welcomed John Robson as a new Trustee. Already a PMR-GCA UK North East Board Member, John is an energetic and inspiring fundraiser – his incredible exploits were featured in our last issue.

There was also the chance to find out more about Trustees' areas of interest. Dorothy Byrne outlined our media strategy; Wendy Morrison spoke about plans for local support groups and Catie Pickersgill, a dedicated Helpline volunteer, described the benefit of our much-needed Helpline – and the positive experience of volunteering.

Members' Day included a presentation on healthy lifestyles from nutritionist Chris Sandel, and a discussion on the charity's development by Sophy Proctor, concluding with a lively group discussion around what specific information people felt the charity should provide on different topics – the results will be used to produce information resource sheets.

The day was also a great opportunity for the charity to ask members what they feel they need, giving us the information we need to provide better support. We'd like to thank everyone who gave their time, energy and enthusiasm to make the day such a success.

Fundraising Updates

Every penny matters when it comes to providing the support, information and advice needed to cope with PMR and GCA. Every month we are overwhelmed by the donations, In Memoriam collections and proceeds of events sent to support the work of our charity. These include a recent 'anti-inflammatory' dinner cooked and hosted by Penny Denby, our newsletter volunteer and North Kent support group organiser.

Our Fundraisers

While we appreciate that the effects of illness mean it is not possible for everyone to undertake fundraising activities, it is always inspiring to hear about people who have committed their time and energy to do so. One excellent example of this is **Jacquie Small**, mentioned in our last newsletter. Here is an update from Jacquie on her progress:

"My training has been going ok. The longest distance I have covered in one go so far is 20 miles. It was tough going and the few days after that was agony. I have now seen a rheumatologist who is convinced I do not have PMR or GCA. He told me I have Fibromyalgia and the headaches are due to the steroids. He was actually quite cross that I had already been on steroids for nearly 3 months. He said I was too young for PMR (at 48). He is insistent that I come off the steroids and go onto pain killers. It was a very tough day as when the nurse weighed me I burst into tears seeing that I had gained almost 3 stone. That on top of my hair falling out, the sleepless nights, the painful days, I had just about reached my tolerance level. I left feeling very let down and isolated.

I have started tapering the steroids and my Thyroxine (I have UAT) stays the same, but not without a price to pay. Pain etc. On a positive note I am a great believer that the mind is stronger than the body and I can overcome the pain and continue with my training and fundraising. As you can see from my page I am slowly reaching my fundraising target -

http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserProfilePage.action?userUrl=JacquelineSmall

On the 28th June my tough journey will start at 7.45am in the morning along the Grand Union Canal where I will keep going for 12hrs in the hope of completing 50k (just over 31 miles)."

May 2014 - Kate Gilbert receives a cheque for £100 for PMRGCAuk from Penny Denby on behalf of the PMRGCA NorthKent Support Group

Research – where does the money go?

We are very grateful indeed to PMRGCAuk and PMR and GCA North East for the donation of £8000 towards research into PMR and GCA. We are especially keen to use this to help fund small research projects for the next generation of doctors who might not otherwise get this opportunity. This year, we'll have two medical students joining our research team in Leeds: Angus Hall, who is studying Medicine at Birmingham University, will be doing a 6-week summer vacation project with us, and Dan Drayton, who is studying Medicine at the University of Leeds, will be undertaking a one-year intercalated Masters degree (MRes) starting in September. These bright and talented youngsters have both been awarded highly sought-after student bursaries from the Pathological Society to help support their work. Angus and Dan will be looking at different aspects of the histology (microscopic features) of temporal artery biopsies, in order to find out more about how GCA develops and why the inflammation within the artery wall can be so hard to shift once it has become established. The donation from PMRGCAuk/PMR and GCA North East will help buy the reagents and other laboratory supplies that they will need to carry out their projects successfully. Thank you very much!

DR SARAH MACKIE, UNIVERSITY OF LEEDS

Alendronic Acid
The Whys and Wherefores

BY EILEEN HARRISON

When we are diagnosed with PMR or GCA the first prescription that is written is for prednisolone – and I imagine everyone knows why.

Then, often there is a whole handful of other stuff: calcium and vit D supplements, omeprazole or something similar and maybe other things too. One of these "other things is "alendronic acid, for your bones" – and that one is often the subject of a lot of controversy.

Our bones are like any other tissue in our bodies, constantly being broken down (a process called resorption) and renewed by new bone forming. To do that a good supply of calcium is needed, mainly from the dairy products in our diet as well as fortified cereals and some dark green vegetables. In the USA orange juice is fortified – but not in the UK.

When we are taking prednisolone it alters the way our bodies carry out several things. One of these is bone resorption. This process increases with age anyway and taking prednisolone speeds it up further while at the same time slowing down new bone being formed. If that goes too far your bones become less dense and you may develop osteoporosis where the bones become brittle and can break easily. Taking extra calcium seems to slow down this process.

Alendronic acid (AA) was developed to help avoid osteoporosis. It is taken up by the bones and by slowing down the resorption process and speeding up the formation of new bone it can even reverse the existing damage. It was launched onto the market in 1995 after a very clever marketing campaign claiming there were no side effects, many doctors were convinced that it could prevent osteoporosis and could be used as "preventative medicine". The patent ran out in 2008, cheap generic versions appeared – and its use in that way grew even further. Other versions of bisphosphonates, as they are called, were also made.

However, when a drug of any sort is being developed, the first time they find out the long term effects is once it has been approved and released for use in large numbers of the general population. By about 2010 it was being seen that a few quite serious side effects were beginning to appear and they started to think again and finally it was recommended that, for the moment at least, it should not be prescribed for more than 5 years.

The reason for giving AA was to "reduce the rate of devastating hip fractures". In fact it doesn't reduce the risk much at all. It was now being given to young women, in their 50s. AA only works as long as you are taking it and that meant these women might be taking it for 30 years or more – and no one knew what it can do over that amount of time, they will have to wait and see. In fact, it looks as if the risk of the nasty side effects (necrosis of the jaw and unusual breaks in the thigh bone) if you take AA for a long time is not so very different from the original risk of the hip fracture it was meant to prevent. Having slightly lowered bone density does not mean you will have a broken hip – and many of us have perfectly normal bone density.

The guidelines from the British Society of Rheumatologists say PMR patients should have a dexa scan soon after starting prednisolone and checked at 2 year intervals. If that is done then they can see who has good bone density – and they do not need to take AA yet. Many patients have good bone density – and many still have good bone density after 5 or more years on prednisolone. If someone has low bone density then there is an argument for taking AA, then they may be at risk – but not necessarily.

Taking AA itself has other downsides. It must not be given to anyone with a history of gastric reflux (heartburn), hiatus hernia or any surgery for such problems. It can cause musculoskeletal pain which can be severe (don't we have enough of that already?). It must not be used in chronic renal failure, nor if your calcium or vitamin D levels are low – they must be checked and put right. Some dentists will not extract teeth for patients who are on AA because they believe there is a risk of the jaw not healing. All of the PMR forums in the UK have threads discussing the side effects patients have suffered.

It is a personal decision, taking it or one of the other bisphosphonates may be justified. There are other drugs available which work in different ways. There are several proven ways of avoiding a hip fracture in later life, such as better lighting, removing trip hazards, wearing shoes not slippers, drinking plenty of water, working on muscular fitness and improving vitamin D levels – all free or cheap and with no side effects!

Eileen Harrison is a graduate physiologist who worked in the NHS for many years as well as having been a medical translator for over 30 years. She herself has had PMR for 10 years

MORE INFORMATION

This a good summary of the evidence about AA – from the non-drug company side.
http://medicalconsumers.org/tag/fosamax/

Pmr Gca SCOTLAND

ALLIANCE HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND member

Dear Readers

A couple of issues ago I mentioned the distances and population spread that we enjoy in Scotland. While support groups are great for people who can access them, for others getting to one is likely to be an impossibility and this is where the phone line becomes a genuine life-line.

I asked one of our volunteers to give me her perspective and also asked a regular caller about her experience.

REFLECTIONS OF A HELPLINE VOLUNTEER

"It is over a year since I joined the team of volunteers who run the PMR-GCA Scotland Helpline. I was first diagnosed with GCA two and a half years ago and a few months later PMR joined the party so I have firsthand experience of both conditions, as well as a rather eventful steroid journey with just about every side effect ever listed. However lousy this was at the time, it has given me a good understanding of living with the conditions. I also enjoyed searching for information on the internet, in medical journals and through meeting many fellow sufferers online via internet forum groups run by PMRGCAuk and PMRGCAuk North East Support. When I felt a bit better I also made contact and visited the Dundee support group and made more friends there which led to becoming a trustee of PMR-GCA Scotland.

"It was still very daunting when I was preparing for my first week on Helpline duty - would I really be able to be of any help? I soon found out that the most important skill was not any learning or research but an ability to listen and try to understand each individual's unique journey and specific anxieties. Each call has also increased my knowledge of the range of problems experienced, and this can in turn help future callers who phone up.

"Obviously none of us are qualified to give medical advice but can offer information from resources such as the British Society of Rheumatology Guidelines, and the various Arthritis Care publications, as well as personal experience and hints and tips from other patients.

"All the Helpline volunteers are encouraged to attend training courses run by The Helpline Association and earlier this year I went to my third class 'Understanding Emotional Content'. Listening on the telephone is so different from chatting face-to-face. No eye contact, facial expression or body language, so it was really useful to learn and practise skills specific to helpline work.

"The best part of being a volunteer is that I have 'met' and listened to many lovely brave people and we have shared a lot of laughs along the way."

SARAH G

THOUGHTS FROM A CALLER

"It is now fourteen months since I started with GCA and having progressed through various stages I now feel it is time to thank you for the help and support given to me by all your volunteers.

"I had never ever heard of GCA and as nothing significant showed up in my blood tests, I did feel at my wits' end many a time.

"I went on line and was so pleased to read about your support, it did take me a few days to call the helpline and I am so happy that I did as I have always come off the telephone feeling a lot better.

"Please pass on my sincere and grateful thanks to all concerned and I send my Love and Best Wishes to you all."

REACHING MORE PEOPLE

Knowing that some form of support is so appreciated by people who do get in touch – I could even say essential for the individual's sanity at times – we are now looking at what we can do to make sure anyone who needs to know we are here is aware of our existence.

By the beginning of May 2014 we had sent information to every GP practice manager in Scotland (approximately 1000 surgeries).

We have been offered, and have accepted, the opportunity to get our leaflets into every DXA* unit.

We are also exploring how to ensure that every rheumatologist is aware of us.

We know that some people sail through the conditions but for others it is not such an easy road. Our Helpline volunteers are standing by in the hope that the message is getting out to those who might benefit from a non-medical perspective.

* Dual-energy X-ray absorptiometry (DXA) is a means of measuring bone mineral density (BMD). Two X-ray beams with different energy levels are aimed at the patient's bones. When soft tissue absorption is subtracted out, the BMD can be determined from the absorption of each beam by bone. DXA is the most widely used and most thoroughly studied bone density measurement technology. The DXA scan is typically used to diagnose and follow osteoporosis.

SUPPORT GROUPS

Things are not moving quite as quickly as we had anticipated, or as our membership had hoped, but the difficulty is finding small core groups in each area who are prepared to make things happen. The charity will do what it can to provide support during the set-up phase and the groups are working hard to move things forward. Please do bear with us as we try to progress.

WEBSITE

Increasingly the internet is a source of information for patients and friends or family. As you will know there is as much misinformation as there is good.We are hoping to completely overhaul our site soon and would love to hear from anyone who could tell us what they want and need to see (there is a survey on the site for this purpose or email info.scotland@pmrandgca.org.uk)

Keep safe and have a wonderful summer.

Bea

Bea Nicholson: Chair of PMR-GCA Scotland

HELPLINE

0300 777 5090

www.pmrandgca.org.uk

Registered Scottish Charity No SC037780

Registered address
Forest Lodge, Foulden, Berwickshire TD15 1UH

EXPERIENCES

When a family member has PMR

My life as the child of a mother with PMR

I first noticed the changes in my mother's body when she could hardly walk while we were on holiday. We were changing platforms at the station and the strange thing was that she didn't have the strength to climb the stairs. Then, when we went see Avatar one evening and had to walk in snow, my mum found it almost impossible.

Mum had realised a few weeks earlier that she had PMR because her shoulders and hips were so stiff. Her mum had PMR so she recognised the symptoms. The trouble was that when she went to the doctor, he told her to take too low a dose of steroids so her condition got worse. One Sunday, she found she could hardly open her mouth. This was a sign she had GCA and her artery was pressing on her optic nerve. She could have gone blind.

At this point, she called a doctor friend who told her to take 60mg of steroids at once. She was on that dose every day for a few weeks and those weeks were rough. Firstly, she got what she called moon face; it was round and puffy. And although she was getting better physically, her mental state was affected. One day on the way to school, a car nearly hit us. Being young, I laughed because I was scared. My mother shouted, "F.... off! F.... off!" We were both shocked because she'd never said anything like that to me in my entire life. When she told the doctor later, he said, "Tell your daughter that's the steroids talking." Luckily for me, once her dose was lowered, she went back to being almost the same old mum.

However, for the next few years, mum was much less active than she used to be because she would get so tired out. We had to cancel a holiday to India because the steroids made her immunity too low. Instead, I went to camp while she stayed at home and relaxed. We did take a trip to Ireland but mum got terrible cellulitis after a mosquito bite and had to stay in bed with her leg up while I went off to do stuff by myself. The doctor blamed the steroids for lowering her immunity to the bite. During all this period, I felt scared for my mother's health, sight and happiness.

Fortunately, PMR goes away so now mum's nearly back to full health and leads a normal life. We've just been to The Galápagos Islands to celebrate.

HETTIE BYRNE

Support group contacts and updates

The very latest information for all support groups can be found at www.pmrgcauk.com including details of speakers and local events. If there isn't a group near to you why not consider starting one – a problem shared is a problem halved! We will help you to get started.

CAMBRIDGE
Organiser: Dale Hodgson
Phone: 0300 999 5090
Email: cambridge@pmrgcauk.com

EAST ANGLIA
Organiser: Maryan Fidler.
Phone: 0300 999 5090
Email: eastanglia-pmrgca@outlook.com

GREATER LONDON
New group just started!
Phone: Sophy on 0300 999 5090 for more information

LINCOLN
Organiser: Rob Murton
Phone: 0300 999 5090

NORTH EAST ASSOCIATE CHARITY
Organisers: Pam Hildreth & Mavis Smith
Phone: 01287 623 334
E-mail: pmrgcafightersne@googlemail.com
Website: www.pmr-gca-northeast.org.uk

NORTH KENT
Organiser: Penny Denby
Phone: 0300 999 5090
Email: northkent@pmrgcauk.com

MANCHESTER & NORTHWEST
Organiser: Ann Chambers
Phone: 01942 895 806
Email: northwest@pmrgcauk.com
Website: www.pmrgcauk-nw.com

PETERBOROUGH
Organisers: Clare Marshall/Lorna Edmonds
Phone: 0300 999 5090
E-mail: peterboro@pmrgcauk.com

PLYMOUTH
Organiser: Sally Ann Morgan
Phone: 0300 999 5090
E-mail: pmrgca.plymouth@yahoo.co.uk

SCOTLAND ASSOCIATE CHARITY
Bea Nicholson (Chair)
Phone: 0300 777 5090
E-mail: info.scotland@pmrandgca.org.uk
Website: www.pmrandgca.org.uk

SOUTHEND/ESSEX
Organiser: Hannah Padbury
Phone: 01702 587 436
E-mail: southend@pmrgcauk.com

TAUNTON
Organiser: Wendy Morrisson
Phone: 0300 999 5090
E-mail: pmrgca.southwest@yahoo.co.uk

SURREY
Organiser: Shirley O'Connell
Phone: 0300 999 5090
Email: surrey@pmrgcauk.com

SUSSEX/SOUTH COAST
Organisers:
Christine Young & Catherine Pickersgill
Phone: 0300 999 5090
Email: pmrgcasouthcoast@btinternet.com

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