



You are **not** alone

Polymyalgia Rheumatica and Giant Cell Arteritis

Newsletter Winter 2014



Merry Christmas

**Need
help?**



**Want
to join?**



Please get in touch:

PMR&GCA UK North East

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www.pmr-gca-northeast.org.uk



The



of Reduction

Over the years, I have exchanged ideas with numerous people. During this passage of time, I have had many discussions with medical people who were interested but very wary and I understand this wariness, because I was a patient and not medically trained.

I discovered that nobody ever talked about 'withdrawal' symptoms when on prednisolone, but withdrawal symptoms occur whenever you are trying to stop using anything you have been taking for a long period of time. I found two people who were also interested in this theory and one of them had already tried a slower way of reducing and found it worked. We are not telling people to not reduce, we are telling them that for a lot of people this sort of reduction works. **So here follows our joint story...**



Prednisolone reduction: worked out by patients for patients (Not approved by the Medical Profession)

PMR, GCA and Prednisolone

As most people reading this will know, when we are diagnosed with PMR or GCA the first step is to be put on a dose of prednisolone (pred) that is high enough to combat the symptoms. This will always be a dose that is known to be high enough to work for most patients and then the next job is to reduce that dose to the lowest dose that manages the symptoms acceptably. This will vary from patient to patient so there is no simple way of knowing that dose. The answer is to taper the dose until you find the right level.

For most of the illnesses where pred is used to reduce inflammation (like asthma or flares in arthritis or Crohn's disease), it is used as what is called a "fast taper": an example would be starting at 30mg for a week, 20mg for a week, 10mg for a week and stop – that is quite safe. The inflammation has been dealt with quickly and you can stop the medication. Because doctors are used to using pred like this they often try to do the same in PMR and GCA and a common reduction would be 10mg at a time above 40mg and 5mg at a time below that. However, the longer you have been taking pred the more difficult the reduction becomes. For one thing, when you are taking pred your adrenal glands do not need to make our body's natural version of pred: cortisol. They have to start up again when the pred is taken away and that takes time to settle down. The second problem is that when you take it for longer your body becomes accustomed to this substance being there – and if it is taken away you may develop withdrawal

symptoms. This isn't addiction; it is just a change that the body has to get used to. Unfortunately, that can cause joint and muscle pain, headache, fatigue, low blood pressure and nausea – all unpleasant and for many of us the same symptoms as we had with our PMR or GCA to start with. And there is a third factor: what is the right level for YOU? The dose that controls my PMR isn't going to be the same as the dose that is right for you.

Some doctors try 5mg steps but most doctors will tell patients to reduce 2.5mg at a time below 20mg/day because it has been known for a long time that if the reduction is more than 10% of the current dose there are more problems. It may work for a lot of patients, especially at the higher doses above 15mg but for many it is too fast and they develop pain and stiffness again – but the problem is to know whether it is withdrawal or is the new dose simply too low to control the inflammation. PMR, in particular, is a chronic problem: as long as the underlying autoimmune problem is active, inflammation will develop if the pred dose isn't high enough to control it.

The bigger the reduction the more likely either problem will be. The body doesn't like too big a change in dose – and although you are fine at, say, 10mg, you may not be at 7.5mg because it isn't enough to douse the inflammation. So you or your doctor decides to jump back to 10mg. The same thing happens the next time you try it – so you end up yo-yoing the dose. And every time it is worse. But maybe a dose of 8mg would be enough – you have just sped past the stop you wanted! In addition,

the lower your dose is, the bigger percentage a 1 mg drop becomes – so how can you make it smaller.

Some years ago a Swedish gentleman called Ragnar found he couldn't get below 5mg without the symptoms returning even though he was only trying to reduce 1mg at a time – so he tried just reducing the dose one day in 3 for a couple of weeks, then 2 days in 3 – and then went to every day the new dose. Doing this he was able to reduce to zero successfully. His story is on the Northeast support group website – and he was the first member of "Club Zero" on their forum.

We knew about his story and often advised people to slow the reduction right down as they got to these lower doses but then we realised that people were struggling long before they got to 5mg: they couldn't get below 10mg and in some cases couldn't get below 20mg when told to reduce 2.5mg at a time. So the advice was changed, if people had problems at any dose we suggested a 1mg reduction and it worked for many. Patients who were struggling to reduce with their doctor's big steps were being told they were "steroid resistant", that they must get to lower pred doses and that they would have to take a "steroid sparer" such as methotrexate. We weren't convinced that was necessary and a few of us experimented with ways to make the drops even smaller and smoother – what we call "Dead Slow and nearly Stop".

There are two versions – the only difference is how we counted and wrote it down. Reduction Plan A is probably a bit slower than Reduction Plan B because it works down from every day old dose to alternate days old/new first, whereas Plan B dives straight in to that. Because of that Plan A could also be used if you can only reduce in 2.5mg steps because you are on enteric-coated pills which must not be cut. You can stop at any time: if you feel you are fine at 1 day old, 2 days new but 1 day old, 3 days new makes you uneasy – that's fine. You are taking less pred. In a month or two you might get a bit lower and manage 1 day old, 4 days new.

We know there are a lot of people using one or other successfully. It would be great to know how many people have managed to reduce further than ever before.

If anyone wants a copy of these two plans, email with the subject heading Reduction Plans.



Mavis R Smith (GCA).

Eileen Harrison (PMR).
Physiology Bsc(Hons) St Andrews
Translator Medical and Science.

NB. Ragnar was the first person and his story can be found on our website.



John Robson: a new Trustee

January 2013, I was a fit and active 51-year-old Fire Officer. My hobbies included running 40+

miles per week training for marathons, rock climbing and mountaineering in some of the world's most remote mountain ranges. I organised events for local charities. Within 2 months I'd lost nearly 2½ stone, I experienced debilitating pains... and was in a wheelchair. In May I was diagnosed with Polymyalgia Rheumatica and started my weird and wonderful journey to regaining my health and fitness. Within 2 years (November 2014) I recovered sufficiently to return to climbing and running.

I realise I had an advantage from the start being a young(ish) man with a very fit body. I also had a strong support mechanism with a close family, friends and colleagues. I was fortunate to attend a Rehabilitation Centre with hydrotherapy and physiotherapy sessions.

I have a lifetime experience raising funds for charity and realise we need to increase awareness of PMR&GCA.



Dr Sarah Mackie: a new Patron

Associate Clinical Professor and Honorary Consultant Rheumatologist.

I am a rheumatologist currently in year two of a five-year NIHR Clinician Scientist Fellowship, which centres around ways of improving the diagnosis of polymyalgia rheumatica (PMR).

Member of group responsible for reviewing and updating the 2010 British Society for Rheumatology PMR Guidelines.

Member of ACR/EULAR International PMR Guidelines Group.

Co-Chair of OMERACT PMR Working Group – working towards a core outcome set for use in clinical trials of PMR.

medhealth.leeds.ac.uk/profile/760/728/sarah_mackie

We are delighted to announce that Sarah Mackie has agreed to become a Patron.

Group news from the North East

PMRGCA UK: Support Group Organisers (SGO) Day

Pam Hildreth was our North East representative at the SGO Day in London on 22 October. John Robson also attended in his capacity as a National Trustee. Although it was a long day travelling from the North East, the venue was ideal in a Community Hall near King's Cross, and Sophy, the PMRGCAuk Development Director, had produced a very constructive and interesting agenda with a couple of workshops.

There was the opportunity to meet old friends, meet new faces and it was pleasing to see the number of groups being established.

There was general discussion regarding all Support Groups and the programme enabled everyone to contribute. The specific presentations were all very well received and evoked good discussion. These included – Safeguarding and boundaries (Clare Marshall, Peterborough), Advertising the Groups (Wendy Morrison, SW) and Fundraising made Easy (John Robson, NE).

There was an opportunity to share ideas, information, tips and tricks regarding all these issues and running the Support Groups. We were so busy that we even worked through lunch looking at some interesting Case Studies around Safeguarding.

The positive enthusiasm from all SGOs is evident and hopefully there is a strong foundation for the national organisation to move forward and develop more effective and efficient support mechanisms to assist local PMRGCA groups.

Pam Hildreth and John Robson



Dr. Michael J Plant MA, MBBS, MRCP, MD, Consultant Rheumatologist and Clinical Director, James Cook University Hospital, Middlesbrough. Dr Plant was Guest Speaker at the last meeting. Dr Plant helped to arrange the very first meeting and also took part in the DVD and the launch at the Centre of Life. It was a very informative meeting and a lively question-and-answer session.



Guest speaker at the last Gateshead meeting was Joanne Hewitt, a registered Bowen Technique Practitioner with

the European college of Bowen studies, established the Bowen therapy clinic in 2004, starting out at Claypath Medical Practice and currently based in Rio Verde, Meadowfield, Durham, just outside of Durham city and NIHP Durham. Joanna gave a talk and a demonstration of the technique. For more information visit www.jhewittbowentherapyclinic.co.uk

Dates for your Diary

Members can attend meetings at either or both venues, so you could attend eight times a year.

Gateshead next meetings

Library, Prince Consort Road
1.30pm start

Monday 26 January 2014

Guest Speaker: Dr Pamela Peterson
Consultant Rheumatologist,
Freeman Hospital, with a special
interest in PMR and GCA

Monday 30 March 2015

Buffet Lunch

Monday 29 June 2015

Guest Speaker: Mandy Ridley
Lead Pain Management Clinic
Nurse Specialist, Queen Elizabeth
Hospital, Gateshead

Monday 28 September 2015

Guest Speaker: TBA

Middlesbrough next meeting

Wednesday 14 January 2015

Post Christmas Lunch 12.30pm

Marton Country Club.

Needs to be pre-booked.

Contact Pam on 01287 623334

My Journey with GCA and Research Trial



I am Gladys Russell, a born and bred Geordie, who lives in Newcastle and was born 71 years ago. Until my car crash in October 2013, I was very fit and healthy.

I had to be cut out of the car and spent a day in hospital having X-rays, luckily no broken bones but I did have whiplash and a 'lame' right arm. Following many weeks of physiotherapy this was all rectified.

I then started having severe headaches, neck ache and shoulder pain and eventually, what I now know as 'jaw claudication'. All the doctor did was to give me different painkillers every week, none of which worked. Finally, the doctor started taking tests and two months later (January 2014) I was diagnosed with GCA.

You can imagine the shock and disbelief as I had never heard of it, but also the relief of finding out the reason for all those symptoms. I was also told the scary news that I could have gone blind before I was diagnosed. I was so lucky.

I was started on 60mg of prednisolone immediately and was asked if I would partake in a trial of new medication, which basically could reduce the need for prednisolone. Not take it instead of prednisolone, just to reduce the long-term need.

After a lot of hard thought and plenty of talk, I decided to go ahead and take part in the trial. Trials of this new medication (Tocilizumab) are 'blind', so I don't know if I am on the new medication, a placebo or just the prednisolone. The trial lasts three years, but hopefully the GCA will be in remission long before that time. I have wonderful support from the medical people at the Freeman Hospital who are running the trial and especially from Heather Russell, the rheumatology nurse, whom some of you have met. Heather is the person who put me in touch with this Support Group and attends the meetings.

I am being very well looked after on this trial, by the Consultants and Heather at the Freeman Hospital. I attend once a month for blood tests and a complete examination of my whole body, which also includes chest X-rays. Currently, I also take Calichev, Ranitidine (old name Zantac) and Prednisolone.

I am able to call the consultant or nurse at any time of the day or night if I am concerned or worried about anything, no matter what. I would say to anyone, if you are asked to take part in a trial, do so, the treatment and support is fantastic. You can also tell your GP and your consultant that if any trials are going you are willing to give it a go. You can always pull out, they don't make you stay; there is no pressure at all just brilliant care.

I had a few hiccups in the beginning and one of them was depression, for which I was given 10mg of Citalapram and I have been fine ever since. I also have borderline Type 2 Diabetes, Osteopenia (for which I have a 3-monthly injection) but those are also under control now. I also inject myself weekly, with whatever I am on in the trial; remember, I don't know as it is 'blind'. The medical people don't know either; we are all in the dark.

After two months I was back to my gym doing, Salsa, Zumba, Yoga, Pilates and Weights.

My diet consists of: Breakfast – Bio Natural Yoghurt, Manuka Honey and Green Tea; for Lunch – fish, chicken or eggs with wholemeal bread, spelt pasta or brown rice; Dinner – curry with rice and lots of vegetables or lean meat or fish with lots of vegetables.

I eat nuts, seeds, flax, bio yoghurt and malt, dark chocolate, oatcakes, and seaweed; 3 glasses of wine per week, de-caff tea and coffee, sugar-free sweets. Once week I juice fruit and vegetables and it last about 3 days.

I have a good social life and quite a bit of energy, the downside is, I have gained weight, for all I watch my intake of food and lost some hair. Must remember to ask if I can have Folic Acid to help hair loss.

I am pleased I found the support group and a wonderful bunch of people who are of great comfort and answer a lot of my questions, and are interested in how I am progressing and are totally there for me.

All in all, up to this point in time, although I would rather have not encountered GCA, my journey has been a good experience. I only wish that everyone could say the same.

Gladys Russell

Donations – their stories... they raised over £4,000.

Jim Aitkenhead

This year we walked the north section of the Pembrokeshire Way, which presents a new challenge as coastal paths resemble long staircases as one descends and then climbs to and from the beaches en route.

Day 0: Arrived at "Oriol Milgi" on Sunday afternoon with a superb welcome to Wales at our "boutique" B&B.



We are all looking forward to the first day's walk fortified by an outstanding and healthy breakfast.

Day 1: St. Dogmaels to Newport. 15 huge miles and 4,000' climb. Hot, hot day. Shouldn't complain about the weather really as it could be rain, rain, rain! First 9 miles were OK, but then seriously tough with toe and foot issues and general tiredness. This walk is hard owing to the constantly undulating terrain, very steep climbs and descents and narrow path which is very hard on the feet.

Day 2: Newport to Fishguard, 14 miles. Thought today would be easier around lunchtime but it turned into another toughie with more foot problems. Cooler and some light rain and a tea stop were a plus!

Day 3: Fishguard to the Aber Mawr, 12 miles, 2,500' climb. An easier day with broader paths, beautiful scenery and seal pups en route. The seals occupy remote beaches where people have no access, but can be viewed from a distance.

Day 4: Aber Mawr to Berea, 12 miles. Drizzly day with everyone tired and achy. Highlight was watching seal pup being given first swimming lesson by mother.

Day 5: 14 miles. Walked into St. David's which is a delightful "city" (due to the Cathedral). We found everything we needed. Our lodgings, a pub and a chemist! Lovely day and sad to leave the beautiful coast. I'm off to soak my feet in Dettol...

This year our team has changed and Gerraint has been replaced with Sarah.

WE DID IT! *70 miles in five days, and still smiling at the end.*

In loving memory of Charles & Freda Aitkenhead

Freda died in June, aged 84. She had breathing difficulties and her heart failed her. However, she died at home and was well cared for. Freda was an out of area member of PMR&GCA NES. Jim's father suffered from Parkinson's illness and the team raise money for both charities.

Jim, Richard, Lindsay and Sarah.

"Running free with a smile again"

John Robson decided to attempt the Great North Run again in September 2014, which would definitely be his biggest and hardest challenge to date as he did not know how his body would cope with running 13 miles... something he used to do 1hr 20mins!

Well John, in spite of still being on a long-term steroid reduction programme and still learning to live with PMR, did run the Great North Run and, in his own words...

What a very emotional and happy day – one that will live in my memory forever. I managed to run free with a big smile and complete the race in only 1hr 51mins and 7029th position. Thanks to all my wonderful and very generous supporters... I could not have done it without you xxx



PMR&GCA UK North East Support Donations&Gift Aid

We wish to thank all the people who have donated monies to us over the past few months. We also wish to thank those taxpayers who filled in **Gift Aid** forms.

Gift Aid enables us to claim **25p** for every **£1** donated from HMRC. Once you fill in a **Gift Aid form** we can claim without you ever having to fill in another form.

Further information on our website:
www.pmr-gca-northeast.org.uk

The Stocken Family



Craig took part in a challenging 100km ultra-marathon following the St. Oswald's Way. Starting at dawn on Holy Island, then following Hadrian's Wall and finishing at Rothbury. Craig came in 3rd and completed the 100k in 11hrs 44mins. He came home famished! So the baton has been officially handed on... One down, one to go, Windermere here I come, it's gonna be a chilly one...

Deb took part in the Windermere Cross Lake Chill swim from Wray Castle to the National Park visitor centre, which is approximately an 1.2 km if you swim in a straight line and avoid the ferries! 8.30am in the mists of Windermere, cold but not choppy, an amazingly friendly event. Loved swimming with my float, I've kept it as a souvenir!



Well done Freya and Gosforth Central Middle School for raising £31.90 with their yummy cake sale, and thank you to everyone who baked!

Ben and Freya

Gentle walking group

When Age UK withdrew the funding for our Nordic Walking Group, we missed our weekly walk and social gathering a lot, so I put out a message to the ex-Nordic walking group, the PMR/GCA support group and friends and family asking if anyone was interested in joining a "Gentle Walking Group" stating:

"We will meet on Friday mornings at 10.30am at the venues on the attached timetable. We intend to walk for approx 1 hour, at your own pace with or without walking poles, with or without doggies. Bring a friend if you wish. We are open to any suggestions for other possible venues, so long as they are reasonably flat walking and have a cafe (or pub) nearby for refreshments after the walk."

The group started mid January and is going from strength to strength. Our venues are usually in the Teesside area. We have walked Guisborough Forest and walkway, The River Tees Barrage, River Tees at Darlington Broken Scar, Stewarts Park Middlesbrough, Redcar Stray and Saltburn Beach. Our trip to Farndale to see the daffodils was the furthest we have travelled so far – it was a wonderful sight to see but it was also the wettest so far.

If you live in our area and would like to join us, please contact **Pam Hildreth** pamhildreth46@virginmedia.com or 01287 623334 for a copy of our timetable.





Time to meet Dan whom we are supporting in his research

I am Daniel Drayton an intercalating medical student at the University of Leeds.

Intercalation is an opportunity for medical students to take a year out of their degree (MBChB) and study something other than medicine. Intercalation is well established and supported here in Leeds with almost half of medical students intercalating before they graduate. I have completed three years of my degree so far. After I have completed my Master of Research in Medicine (MRes), I will have two further years of study before I qualify as a doctor.

My drive to do research developed following a guest lecture given by someone from the national institute for clinical excellence (NICE). Research is an integral part of medical practice, it forms the basis of our understanding of disease and the platform from which we prescribe and treat our patients. I was keen to learn more about research and investigate what role it may have in my personal career path. Following the advice of Dr Sarah Mackie (now my project supervisor), I applied for the MRes which is largely assessed based on a 9-month research project. I spent last year meeting various members of the Lab team and my other supervisors; Dr Darren Treanor (histopathologist) and Dr Aruna Chakrabarty (neuropathologist), as well as Professor Ann Morgan (rheumatologist). So far this year we have met several times to refine and plan the direction of the project. I always look forward to the meetings; there is something exciting about conducting new research in uncharted territory.

As Dr Mackie mentioned in her last newsletter, we will be spending this year trying to learn more about Giant Cell Arteritis (GCA). We will be using software created by a collaborative project between the School of Computing and the Virtual Pathology department at the University of Leeds. The software will allow us to create 3D images from parts of temporal artery biopsies that patients have undergone as part of their routine clinical care. The patients have all agreed to take part in an ongoing research study that is being run by the University of Leeds.

Because larger arteries have thick, muscular walls, they need their own tiny blood vessels, which are called vasa

vasorum. These tiny vessels run over the outside of the arterial wall to keep the wall well-supplied with oxygen. It is currently thought that the vasa vasorum are a major route of entry of the white blood cells that cause the "arteritis" of GCA. Once the arteritis of GCA has developed, extra tiny blood vessels can grow inside the artery wall as a result of the inflammation. This is called angiogenesis and it is thought to be a factor in why GCA can be so hard to treat. In my project I am going to be studying the anatomy of these tiny blood vessels, both the vasa vasorum that exist in healthy blood vessels and the pattern of angiogenesis seen within arteries affected by GCA. We hope that by observing these changes we can shed further light on the cause of GCA. If we can better understand what causes GCA, then this might help researchers figure out how to develop better treatments.

As far as I know, nobody has used this type of software before in GCA. As a result, it is taking me time to figure out the best way of doing it. The software allows the tiny vessels to be highlighted, but the temporal artery is huge in comparison. It has been challenging to try and find all the tiny vessels, like finding not just one but several needles in an enormous haystack!

I have already gained a better understanding about the process and realities of undertaking and publishing research as well as practical laboratory skills. The combination of project work and deadlines set by the university are challenging and developing my time management skills. Although I know this year will be tough, I am excited to continue learning and developing my existing skills. Not only will I graduate a more competent researcher, I know it will help me be a better doctor in the future too.

Also, I learnt a great deal applying for funding from PathSoc – The pathological society. I successfully obtained the scholarship which is in addition to support received from PMR & GCA North East and have made studying this Master's degree possible, for which I am exceptionally grateful.

Daniel Drayton

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