

Lancashire & Cumbria Branch
Guillain-Barré & Associated Inflammatory Neuropathies (GAIN)
Bilsborrow Village Hall
Bilsborrow
Near Preston
PR3 0BL



NEWSLETTER 2017

BRANCH AGM & JUNE OPEN MEETING



It's difficult to believe that summer has begun and many people will be looking forward to their summer break. For those who are fortunate to have already been on their sojourn, we trust it was an enjoyable and relaxing time. There will also be those who are still to travel to climes near and far, so for all of you, we hope it will be the holiday experience you hope for.

The committee members are always overwhelmed by the devotion of our members, this was proved with so many making the journey on a beautiful, sunny June afternoon to our usual venue in Bilsborrow, near Preston for the branch AGM and the second of our quarterly meetings this year. Sybil, our Chair and the committee warmly welcomed members as they arrived. It is always particularly good to see the familiar faces of our regular members and to hear their tales since last we met. We were pleased to give a very warm welcome to Ann Pennington and her sister Judith, who were attending an open meeting for the first time. Both told us they had learned of the branch from staff at Royal Preston Hospital (RPH) and GAIN head office, adding that their sister was being treated in RPH for Guillain-Barré syndrome. Both ladies added that they had learned so much from mixing and talking to others who had been through a journey with GBS, they concluded by saying how enjoyable the afternoon had been for them.

It is customary at the branch AGM for a trustee from GAIN head office to join us, sadly this year we were disappointed that no-one was available to make the journey to Bilsborrow.....but we sincerely hope to welcome a representative in 2018. Prior to the start of the AGM, a minute's silence was held in memory of our dear friend and respected colleague Ann Birchall, this allowed everyone to remember Ann in their thoughts and recollect their own personal memories of her.

Sybil began the meeting with the Chair's annual report; this gave a résumé of events during the last year and her expected forecast for the year ahead. Sybil praised everyone involved with branch affairs, adding how immensely proud she was that the previous twelve months had been so very successful and productive for us. Adding that the Lancashire and Cumbria branch is the only committee led one within GAIN, which for a small branch such as we are, is quite an achievement.

During 2015 / 2016 we had welcomed excellent speakers covering a range of topics, our Q&A Forum remains hugely popular and had covered many various queries from the floor. Some of our Branch members who are also GAIN peer support volunteers had applied for and received health clearances from the Occupational Health department at Royal Preston Hospital to allow visits to patients on the wards affected by GBS, CIDP and other associated neuropathies; however, as of late October 2017, they find themselves awaiting a meeting with Dr John Nixon to, hopefully, complete the process. Steady progress with 'Rosie's Project' has continued in conjunction with the University of Cumbria, Lancaster campus, co-ordinator Rosie Hyslop provides regular updates. Finalising her report Sybil sincerely thanked the members of the committee and all branch members for their continued support and help.





Following Sybil was Branch secretary, Gerald Wilson who gave his coverage of the year's events, this mirrored Sybil's résumé and sentiments. In lieu of not having an attending trustee at the AGM, Gerald read an overview of affairs from GAIN Chief Executive, Caroline Morrice. This reported on the growth of people accessing the GAIN website, while the popularity of the charity's Facebook pages showing substantial increase, sadly those requesting face to face contact for a sufferer had decreased. Carrying on, we learned how the GAIN website is being updated and forums for sufferers / volunteers being developed. The free phone Helpline will now only be available during office hours, and ended by announcing no national event will take place this year.

Updating everyone on branch finances, Treasurer, Joan Haresign thanked everyone for their generosity and hard work during the last year, Tim Hoyles was given a particular mention for running the raffle so diligently at each meeting. Joan also mentioned Sybil's contributions to the branch, not only as Chair but her skills in sewing, gardening, garland making and of course, her famous jams and chutneys. At each meeting jars of the scrumptious delights, in a range of very luscious flavours can be found - their popularity is marked by the speed they are purchased. Each year prior to the June meeting, Sybil is in her garden digging up and repotting plants, these and others brought by members can also be purchased at the meeting. Others were thanked by Joan for various efforts towards fundraising, including sales of jewellery and other items brought as gifts, 5p's collected in a bottle and empty ink cartridges for recycling. One of our talented members makes beautiful handmade greeting cards, Christmas cards and other hand-crafted items - which create a pretty and colourful display - all of these are appreciated so much. Joan ended her yearly account with a few words about our late colleague and friend Ann, saying we send grateful thanks to Ann's husband Colin and family for choosing the branch initiative 'Rosie's Project' alongside Macmillan Nurses to benefit from the donations received in Ann's memory.



Following on, an update on the 100 Club was given by its co-ordinator Glenis Gill. Everyone was thanked for repeatedly renewing their annual subscriptions. Glenis does a sterling job handling the renewal forms and is responsible for sending the prizes out to the lucky winners. She is also a stalwart at fundraising, setting up a variety of gift items at each meeting. Glenis also helps Tim with the raffle tickets and is often found helping with refreshments – in fact, she is a good all-rounder! Glenis always has a smile and is ready to have a few warm words with everyone, she is a real treasure.

Sybil then handed over to Rosie Hyslop for an update on the branch initiative 'Rosie's Project'. Rosie explained about a meeting she had attended at the University of Cumbria, Lancaster, where discussions had taken place for the production of an 'app' or possibly a web link. As the wheels roll forward on the project, up to date information will be announced as they occur with a concise account being printed at a later date. Rosie asked members for any suggestions to be considered for inclusion in the specification which will be submitted to the university. To Rosie's surprise there were many ideas put forward, she was very pleased when these in turn led to a mini discussion that had the potential to carry on longer than anticipated.

Members of the committee confirmed that they were all willing to stand again in their committee roles. Paul Alty, a regular member of branch meetings, attended his first committee meeting last week; we hope he gets as much enjoyment from the meetings as we all do. For those new to the branch and to remind everyone of the committee members and their roles, we have compiled the following list: Sybil Loxam - Chair, Gerald Wilson - Secretary, Joan Haresign - Treasurer, Glenis Gill - 100 Club Co-ordinator, Tim Hoyles – Regalia Co-ordinator and Raffle Organiser, Rosie Hyslop - Rosie's Project Lead, Newsletter Editor and last but not least Paul Alty – Committee Member.

Waiting patiently for the AGM to be concluded was our guest speaker Pat Ascroft, MENCAP representative and fund raiser, whose talk on her experiences Dog Sledding in the Arctic.



Following a warm welcome from Sybil, Pat explained she had never envisaged a future filled with hoovering, dusting and other domestic duties as she got older, none of those were on her agenda. Being involved in fundraising for MENCAP has brought opportunities to travel to faraway places and experience things that would have made a far younger person tremble at the knees, her travels to Japan and Cuba to take on challenges and trekking in Patagonia were all quite moderate compared to this latest endurance fete.

Pat's new challenge began before she left Lancashire; she had to be at the peak of fitness before she could travel and so the services of her niece as personal trainer were engaged. The date for leaving on this next adventure arrived swiftly and Pat, always one for travelling cheaply, caught the overnight National Express bus to London. Gate 23 at Heathrow airport was the meeting point for the party, on approach Pat saw there were seven of the fittest people she had ever seen, on drawing closer to them, Pat

interpreted their expressions as saying 'wrong party, this isn't the Saga holiday group'.....the party consisted of eight plus a doctor, it was established the doctor specialised in amputations....the first of Pat's worries had arrived!

Flying out to Stockholm, Sweden and then on to Kiruna, it was more than evident temperatures had begun to drop and were reaching lows of -15 to -25. The home base and kennel is about 200 km above the Arctic Circle. All guests are welcomed to the guesthouse "Mushers Lodge" where the party met their guide Daniele, who with her colleagues runs 'White Trail Adventures'. It would be from here that the trek would begin; along the trail beautifully situated are cosy wilderness camps, with no running water or electricity, the omission of these essentials added a lot to the spirit of the tour.

At the kennel, 75 Arctic Huskies are housed, living all their lives in a wooden box, it was stressed that the dogs would not win Crufts, their role in life was to sled. Each traveller had a team of four dogs, all of them were important, but the two lead dogs were vital to safety, as they can sense thin ice 20m ahead. Pat explained how layers of clothing, all wool are best and of course waterproof. The teams would sled for 7 / 8 hours each day, on the off chance of an accident all were told not to let go of the sled, their journey took them through spectacular scenery with lakes and forests and across isolated tundra....most of the time the Arctic journey was in complete silence. Soon Pat's journey was over and she returned in one piece back to Lancashire and thankfully, without injury. Sybil thanked Pat so much for sharing her experiences with us; her talk was hugely enjoyable and so very humorous, it is only right to say that the audience were completely enthralled!

We are pleased to announce that Pat will be giving another of her wonderful talks at the meeting on 3rd March 2018.

If you missed the Arctic talk, make sure don't miss the next one!



Soon it was time for refreshments, we are very fortunate to have such talented bakers, once more they provided us with savoury and sweet treats, and we had delicious strawberry scones, chocolate cake, Victoria sandwich and a very luscious carrot cake to go with our tea and coffee. During refreshments, it was Tim's turn in the spotlight drawing the raffle numbers - we don't know how Tim manages to provide such an array of prizes....but we thank him so very much for this outstanding contribution. Also, on behalf of Tim and the committee grateful thanks also go to everyone who donate to the raffle, these are hugely appreciated and add to the variety of prizes.

It is always lovely to witness everyone mingling and chatting together, the essence of our meetings is to help those attending (if we can) with any query they may have and if we don't have the answer we will endeavour to access it through our contacts at head office. More importantly we offer friendship; support and unity to those affected by GBS and variants, and provide advice and help to their families and friends when required through our own personal experiences and knowledge.

[We must emphasise that none of us are trained medically and therefore cannot provide any diagnosis or help / advice on medications or treatments, anyone with such queries should seek advice from their consultant, hospital doctor or GP.](#)

SEPTEMBER MEETING



Well, summer was nearly over and the date for the meeting had arrived very swiftly, which, for many of us means the summer holidays will have become a distant memory.

Once more, Sybil gave a very warm welcome to all attending, and followed on with an update of branch news. One unexpected announcement was the resignation of Branch Secretary, Gerald Wilson. Highlighting how efficient Gerald had been in his duties, Sybil added that he was always up to date with everything and took on a lot of responsibility in his role. Adding that it was hoped Gerald and his lovely wife Fiona will continue to come to meetings. Fiona was a great support in the kitchen and always helped in way she could. As the position is vacant, we would welcome contact from anyone who may be interested in taking on the role. More details can be obtained from Sybil, whose contact details are on the last page of this newsletter.

A warm welcome was extended to Paul Alty who attended his first committee meeting during the week. Even though Paul is new to branch affairs, he has wasted no time engaging in fund raising for us. After seeing an advert in the **gain4all** magazine about recycling old and unwanted mobile phones, computers, laptops, game machines and games, clothing, watches, jewellery and so much more, Paul contacted the company and has received collecting bags. So, if you have any items listed above please bring them along to our meetings....you'll be supporting a very important cause!

Our talented Chair, Sybil has recently made a lovely framed collage from duplicated photographs of branch members and the committee which were captured by our late colleague Ann Birchall. It's a lovely pictorial history of the branch, and was on display for the first time at this meeting, it will be permanently on display at all of our open meetings.

Our guest speaker Ruth Gibbon, whose talk Eat Well, Feel Good was awaited with anticipation by everyone. Ruth gave an insight into her work role with the Meat and Livestock Commission. We all agreed how in times past, recipes had usually been handed down through generations with many children being taught to cook by their mother or Grandma – this, sadly was now a rare occurrence, especially after the emergence of supermarket 'ready meals'. The talk next moved on to vitamin content in foods; Iron in particular caused much discussion. The hierarchy of iron rich foods are as follows: Beef, Lamb, Pork, and Poultry - with the wings and legs giving the most iron, along with oily fish - tuna, mackerel etc. One member raised the question of the best diet for those recovering from GBS and other associated neuropathies, in response Ruth highlighted the importance of potassium, which is found in bananas; adding it was important to eat a good, mixed variety of foods, keep moving, maintain a normal body weight and to avoid processed foods. Also raised was the butter vs spreads debate, to which Ruth told us that she always uses butter, 'After all' she said, 'why would anyone want to consume by-products of the petroleum industry'. This certainly gave everyone food for thought.



Refreshments were served during the latter part of the talk, which gave our speaker the chance to mingle and chat to everyone. It was during this time the 100 Club was drawn and our lucky members whose numbers were picked would have received their prizes through the post. Congratulations to all of you!

The Christmas Party will take place on Saturday 9th December at our usual venue, Bilsborrow Village Hall, beginning at 2pm. Those who have attended at Christmas before will know the party is always full of fun and laughter and as branch tradition dictates, we will be having our annual Tortoise Drive and Jacobs Join. The Jacobs Join is a veritable feast of savoury and sweet offerings to partake of, mostly made by the ladies of our committee and branch members.



Once more, Sybil and everyone on the committee extend their sincere thanks to everyone for making our meetings and the branch so successful. We are indebted to all of you for everything that you do, there are so many of you who warrant a personal thank you, but as we don't wish to single any one person out, we reiterate once more our more than grateful thanks to everyone.

Sybil and the committee wish all of you a very happy and peaceful Christmas and a healthy and happy New Year!



LANCASHIRE & CUMBRIA BRANCH CONTACT DETAILS:

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Branch Secretary – Position Vacant

GAIN CONTACT DETAILS

Guillain-Barré & Associated Inflammatory Neuropathies is a registered charity that offers support and information for those who are affected by Guillain-Barré syndrome, CIDP and the associated inflammatory neuropathies.

For further information or support, please contact GAIN head office:

GAIN, Woodholme House, Station Rd Business Park, Heckington, Sleaford, Lincolnshire. NG34 9JH

Tel: 01529 469910 **Helpline:** 0800 374 803 **Email:** office@gaincharity.org.uk **Website:** www.gaincharity.org.uk

2018 DIARY DATES

Saturday 3rd March
Speaker: MENCAP representative
Pat Ascroft – My Tall Ships Experience

Saturday 16th June
AGM, Plant Sale &
A Mystery Guest Speaker

Saturday 15th September
Speaker: To be Confirmed

Saturday 8th December
Christmas Party
Tortoise Drive & Jacobs Join