

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



WINTER 2017 / SPRING 2018 NEWSLETTER

CHRISTMAS 2017



Our 2017 Christmas party and Jacobs Join saw its attendance affected by the forecasted weather for the weekend and illness. However none of this dampened our determination to celebrate the forthcoming festive season with laughter and enjoyment. By the time our guests arrived, the hall had been festively dressed and the tables adorned with modern costume jewellery and other items suitable for Christmas gifts, all of which had been generously brought by Glenis our 100 Club co-ordinator. Another table bore Sybil's homemade jams in a range of luscious flavours - made from fruits grown in her garden, along with a range of festive garlands handmade from locally foraged moss, pine cones and greenery and decorated with festive embellishments. We also had a table strewn with an abundance of regalia items ranging from Christmas cards, gorgeous tortoise soft toys, egg cups, mugs, key rings from the new range of products. The raffle is always very popular at our meetings, and once again we can't fail to mention Tim, who provides the most amazing range of prizes for this event.

After giving an official welcome to everyone, Sybil gave a few short announcements covering branch affairs, and expressed disappointment that our expected guest Caroline Morrice, GAIN Chief Executive, had been a casualty of the weather and was unable to be with us due to the impact on her journey from Lincolnshire. However, we are pleased that she will be joining us at our branch AGM in June.

The Tortoise Drive followed - for those of you wondering about the term 'Tortoise Drive' - it is the branch version of Beetle Drive. At this meeting the prize for the highest score went to Tom and by a total coincidence - the consolation prize for the lowest score went to his daughter Lynne. Everyone was surprised at the arrival of Pat Ascroft, who had been our guest speaker in June 2017 when she gave a humorous account of dog sledding in the Arctic. Pat very kindly took to the floor again, to tell us, in her own inimitable style, about a recent Royal mission she had been on in celebration of her charity efforts. This time her adventure wasn't to a far flung land to bravely face unexpected dangers.....although some of you may disagree when you read that this trip took her to London! An official from MENCAP had asked Pat and others from the charity to make this journey to attend a special reception celebrating the charity's 70th anniversary at Buckingham Palace and hosted by HRH The Countess of Wessex. Pat's fundraising which has spanned over 20 years, has raised more than £40,000 via her various challenges and presentations. Expressing her delight at attending the celebrations, it was evident it had been a huge thrill for Pat, especially as she was one of a handful of people chosen to meet and chat with the Countess.

Soon we were all tucking into the delicious contributions brought by our members and ladies of the committee for our Jacob's Join, this gave everyone a chance to chat and peruse the stalls, before long we bade our final goodbyes and wished everyone a Merry Christmas and a Happy New Year.

Running as a GBS Recovery Aid by Mike Hunt



In 1988, when I was forty-eight, I picked up a virus that led to total paralysis. After six weeks in an ICU and five months on the wards and in rehabilitation centre, I returned home, together with a wheel-chair and crutches. My recovery, which included learning to walk again, will be familiar to anyone who's been involved with GBS and its aftermath.

Six months later I was back at work, but I never recovered fully physically - I still have numbness from below my knees and wrists - so, faced with a lot of extra spare time, I joined a creative writing course, which led to novel writing and a mini academic editing career.

Knowing how important exercise is, I also joined a gym; but my biggest problem was walking, since I couldn't flex my left foot, my right was weak and I could only manage short distances. In 1997, though, I developed arthritis, which affected my gym work, therefore, when an attendant suggested I try the treadmill I was sceptical. But after my first few steps I found that by holding the supports I could walk reasonably well. On my next session, I speeded up and broke into a trot. Surprisingly, I found running to be easier than walking. Then I tried running on a safe, flat canal towpath and, after a couple of weeks, I tackled the hills of our country park.

In 1998 I ran my first half-marathon - the Great North Run. I'd also found a running partner and in the next couple of years we ran several half marathons. In 1999, I managed my first full marathon - the hilly Stoke-on-Trent one - and then the New York marathon. Although I no longer do very long runs, I still manage my regular six mile routes and our local annual 10k. I've always kept a running log and by April 2018 I'd reached 13,500 miles. If anyone had predicted that when I broke into a trot on the treadmill in 1997, I'd have thought they were crazy.

I've found running so much easier than walking because it doesn't require much foot-flexion, so it's not as affected by foot-drop, whereas running uses my thigh muscles much more and it also reduces wear on my knees. If you're thinking of running, though, do be sure to discuss it with your doctor or physiotherapist and start very, very gently. You might also find it easier if you have a running partner. I strongly recommend keeping a running log, because over the last twenty-one years it's become my spur, since I can see my progress at a glance and it will show up if I start slacking.

Incidentally, I think running may have cured my arthritis.

TIP: because of my foot-drop I had frequent falls which took some time to remedy. Then I discovered the Ossür 'Foot-up'* - a very simple to use two-piece device that fits under shoe-laces and wraps around your ankle and is safe for both walking and running. I also shaved the tread from the toes of both shoes. Since then, I've had no falls at all.

If you're recovering from GBS you may think running is a bit extreme, so try swimming, cycling or gym, or chair-based, exercising - whatever suits you best. It's also important to keep your mind busy, too - an effective exercise for that is writing - either your memoirs, poetry or stories, short and long **.

* Ossür has a UK base and can be found on the Internet. **My novels, *Matabele Gold*, *The African Journals of Petros Amm*, *Two Days in Tehran* and *The Other Self of Lenny Benjamin* (coming soon), can be found on Amazon under Michael J. Hunt if you are interested.

MARCH 2018



Unfortunately, due to more adverse weather conditions, the committee had to reschedule their quarterly, evening meeting to before the Saturday open meeting; this allowed time to go through the agenda, and cover the important items before our members began to arrive.

The meeting began with Sybil thanking those who helped arrange the meeting room, she followed this by warmly welcoming everyone, including ex-committee member Colin; he and his late wife Ann were stalwarts at our meetings and always on hand with warm smiles and welcoming words....we hope we will see Colin at future meetings. It was especially lovely to meet those who had made the journey for the first time; we hope they found the meeting informative, concluding Sybil gave a short resumé of branch news.

Once more we welcomed our speaker, Pat Ascroft, who reflected on her journey in guiding and how it led to meeting a lifelong friend from Argyllshire, which in turn led to her owning a cottage in the Argyles of Bute in Scotland. Her talk was given in her own inimitable style, part in her local Lancastrian dialect and part in Scottish dialects; she also 'acted out' various funny incidents and covered the way of life in the area, the local people and customs. Pat also explained how fortunate she had been to see Golden Eagle chicks in the wild, witness the regular arrival of 'The Waverley' paddle steamer and meet memorable local characters - there was so much more to Pat's talk that it would fill a whole book to document it all.



The Q&A session was held next, this raised the issues of random pain in hands and feet, sensory nerves and various textures causing problems - also discussed was the issue of pain relief.

We must emphasise that none of us are trained medically and therefore cannot provide any diagnosis, help / advice on medications or treatments. Anyone with such queries should seek advice from their consultant or GP.

At this point we must give a great big 'thank you' to the people who fundraise for the branch; we were delighted when committee member Paul Alty raised monies by recycling household items, his friend Andy Goodyear took part in a charity race and divided the amount raised with ourselves and another deserving charity. Thank you all so much!!

While the refreshments were prepared and the raffle drawn, we found time to chat with friends new and old. However, much too soon it was time to wish everyone farewell and a safe journey home.



FIRM FRIENDS

Regalia Officer / Raffle Co-ordinator Tim Hoyles (centre) and founder member of the Lancashire & Cumbria branch, Audrey Ashby are shown in the photos above. Over the years both have become very firm friends, they always create mayhem and much jollity in their little corner; Audrey is Tim's 'little helper' and looks after the raffle tickets and regalia sales at each meeting.....both have given so much to the branch since becoming involved, that we would like to take the opportunity to say 'thank you'.

Our branch AGM will take place at the June meeting, Sybil and the committee will be briefing everyone about the past year along with our hopes for the coming year. Rosie will be giving an exciting update on 'Rosie's Project' and we will be welcoming Caroline Morrice, GAIN Chief Executive, so please do come along to say hello.

IMPORTANT NOTICE

Due to the General Data Protection Regulations (GDPR) that came in to place on 25th May, if you are not a member of the charity you will no longer receive a copy of this newsletter. If you wish to carry on receiving up to date information, magazines and the branch newsletter you will need to complete and return the form that is available from GAIN head office, their contact details are shown below. Membership is completely free and will ensure you remain up to date with all the news from the charity and the Lancashire & Cumbria branch.



Sybil and the committee gratefully thank everyone who helps with the washing up, tidying the room etc. at each of our meetings; it is of huge help and it is appreciated so very much.

2018 MEETINGS

Saturday 16th June
AGM and Plant Sale

Speaker:
Dennis Moore
Laughter is the best medicine

Saturday 15th September
Speaker to be announced

Saturday 8th December
Christmas Party & Jacob's Join

MEETING DATES FOR YOUR DIARY 2019

Saturday 9th March, Saturday 15th June, Saturday 14th September, Saturday 7th December

CONTACT DETAILS FOR THE LANCASHIRE & CUMBRIA BRANCH:

Chair, Sybil Loxam - sybilloxam152@gmail.com Secretary, Ann Pennington - annpeni@hotmail.com
(To be confirmed at the AGM)

**For further information or support,
Please contact GAIN head office using the following:**

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

Tel: 01529 469910 Helpline: 0800 374 803

Email: office@gaincharity.org.uk Website: gaincharity.org.uk

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