

Winter Issue Newsletter 2017

Welcome to our latest newsletter with updates of the branch news, there are two a year and we hope you find them interesting. Although Guillain Barré Syndrome is a rare illness we continue to welcome new attendees at our branch meetings. An important part of what we do is help and support for both regular and new GBS/CIDP sufferers. Our meetings usually include a speaker and we have had a variety of interesting topics in the past. We hold a discussion where we exchange experiences and ask questions or offer tips on GBS-CIDP, new attendees find it very helpful as there can be so many various significant residual symptoms following the illness, not forgetting the different stages that can be experienced on the emotional side. We understand what you've been through, our lives having been turned upside down and everything taken away at the height of the illness. Our meetings are very encouraging and proof there can be a good recovery, and to see so many GBS/CIDP attendees under one roof is inspirational. We do welcome anyone who wishes to attend!



Rosie's Project is still at the fore and has gained ground with a recent meeting held at the Lancaster University of Cumbria in Lancaster. Caroline Morrice, Director of GAIN Charity and Rosie Hyslop committee member of Lancashire and Cumbria Branch met with senior lecturers in nursing and business development managers at the University of Cumbria. The purpose of the meeting was to discuss 'Rosie's Project' and the possible development of a top up training course for health professionals wishing to enhance their knowledge of Guillain Barré Syndrome and associated neuropathies, while on completion acquiring degree level accreditation. During the meeting a couple of very interesting ideas were put forward, both of these were felt to have sufficient standing and longevity, and would fit the mantle of 'Rosie's Project' ideally. The two suggestions are an exciting development for the Lancashire and Cumbria branch and GAIN head office. Caroline will present them to the GAIN trustees at the end of October for approval and a progress update will be announced after this meeting.

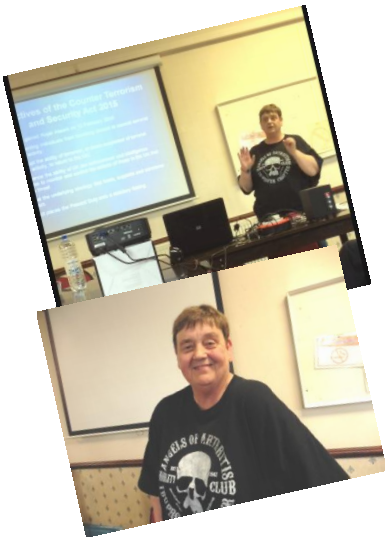
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After previous meetings affected by floods and snow it was good to welcome the sunshine for the quarterly Lancashire and Cumbria branch meeting on Saturday June 18<sup>th</sup>, which appropriately was a plant sale and a demonstration from local gardening expert and poet Mr Tim Smith. Tim's talk was full of gardening tips and observations on life as he set about constructing two beautiful pots, each one to a carefully chosen colour scheme, using to our surprise mostly perennial plants. His talk was enjoyed by all and the two pots generously donated to the raffle were swiftly taken by the first two tickets out of the draw. We moved on to our regular Sufferers and Supporters forum, when we exchange experiences, questions and tips on living with GBS and CIDP. Finally we tucked into beautiful scones with strawberries (thank you Rosie) cakes and tea and coffee as we completed the draws for the '100 club' and raffle, spending our final pennies on plants and preserves.



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At the September meeting we were pleased to welcome our regular member Jacqui Hughes who gave us a fantastic power point presentation and talk on her work in training teachers about countering radicalisation of children. Jacqui explained about the growing national concerns relating to Radicalisation and Extremism. She outlined the approach being taken by schools to prevent young people being drawn into extreme views and groups. It was particularly interesting to hear about the government strategy for tackling extremism and also how the New PREVENT strategy has developed through lessons learnt in previous incidents. Social networking has given more opportunities to become radicalised which parents should be aware of. Educating our children in a safe environment both at school and home is important. Members found Jacqui's talk very interesting which prompted lots of questions and extensive discussion after the presentation. Sybil thanked Jacqui stating she could have listened to her for much longer.



Next we came to the forum and one of our members gave an update on her father who has GBS and has been in hospital eighteen months. She gave an account of when he first became ill, when he first moved a thumb to finally going home recently. We are hoping he will be well enough to come to our Christmas party in December.

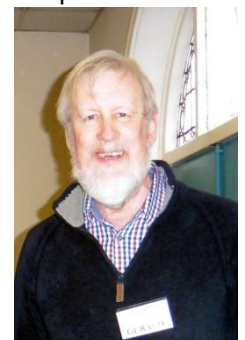
Regular members Margaret and Peter Sandiford were thanked for the monetary gift they presented to us. In the summer they hold a garden party, and Margaret is very talented with art and crafts that she sells for our charity. Our grateful gratitude goes to both Peter and Margaret.

The afternoon rounded off with some delicious refreshments as Tim and Glenis drew the raffle and 100 club, members finally had the chance to browse Margaret's card and handicrafts stall and Sybil's delicious jams and preserves.

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Report on the 'gain2gether' conference held on 25<sup>th</sup> June 2016 by Gerald Wilson

As Fiona and I sat on Preston Station waiting for our train to Glasgow for the GAIN Glasgow Day Conference, we wondered whether the day after the Brexit vote was really a good choice of time to travel to Scotland. Should we have brought our passports? Added to that there had been flooding on the line. Well, didn't David Cameron predict the end of the world? Being in good time, we watched the train before ours, the sleek Virgin Voyager, come and go, before our not so sleek Trans Pennine Express appeared. All aboard, and, know what, there's more space than on a Virgin! So off we rattled, waving to Sybil as we passed Carnforth, and eating our lunch as we approached the border. Then came the voice of doom...border closed?...the train manager announcing problems on the main route up to Glasgow and that the virgin ahead of us had to divert to Edinburgh. But, not to worry, our plucky little Transpennine, "Thomas the Tank", was able to traverse smaller lines up to Glasgow and we arrived only 20 minutes late, allowing us plenty of time to find our hotel, have a stroll along Sauchiehall Street and have a very nice meal before turning in.



Up bright and early the following morning as we were collecting Sybil from the station, before finding the conference in a characterful part of the University, where we met up with other branch members, John Haresign and Norman Druce. With about 100 present, this one day event followed on from a big international medical conference, which included one day entitled "GBS 100", marking the centenary of the original 1916 paper from Drs Guillain & Barré describing Guillain-Barré Syndrome. The medical conference had been attended by some 400 people from 33 countries and we were lucky enough to have some of these world experts addressing us on the Saturday. The speakers, who included our own MAB (Medical Advisory Board) members, Professor Hugh Willison and Dr Rob Hadden, made presentations covering the history of GBS and its treatment, latest research into its causes and progress and potential future treatments. The big hope in future treatment is a drug called Eculizumab, which was developed a few years ago for an extremely rare genetic condition called PNH

and is currently being tested in Glasgow and Japan as a quick means of turning off GBS. It is currently described as “the most expensive drug in the world” and costs some £0.25m per treatment, but we were assured that when it finds more applications the price will come down. Incidentally professor Willison said that world-wide there were about 100,000 GBS cases per year and that there were hospitals in places like Bangladesh and China which admitted one case per day.

The IGOS (International GBS Outcomes Study), which analyses past experience of the progression, treatment and recovery from GBS, has now recruited some 1300 patients into the study with a target of 1000 useful data sets achieved. The largest cohort comes from Bangladesh. A long-awaited first report on the IGOS results is expected later this year. There were also some detailed presentations on the connection between Zika and GBS from the epidemic in French Polynesia in 2012/2013, when 42 GBS cases were identified resulting from Zika. Other interesting papers included “A Patient perspective” from a doctor with CIDP, “History of GAIN” from GAIN founder Glennys Saunders, and “GBS in Animals” from a vet (dogs, cats, chickens, chimpanzees, and goats have been recorded with it). The graveyard (post lunch) slot was enlivened by something called “Exercise for All” which was literally was that with loud music and Zumba type exercises led by extrovert occupational therapist, Santo Garci. So no post-prandial snoozes!!

The main event concluded about 4pm and we moved on to the GAIN AGM with about 40 in attendance. This passed quite quickly with one of the few points of discussion being a motion, which cancelled any need for a quorum (currently 28) at a General meeting. In view of the difficulty in getting a quorum for recent AGMs out of the 265 voting members of the charity, this seemed in my view to be the only pragmatic way forward and was passed. Finally it was noted that our friend and several times visitor to our branch, James Babington Smith, is retiring after 8 years as GAIN Chairman with time before that as Office Executive. A vote of thanks and presentations were made.

On Saturday evening there was a very nice dinner at a hotel which included a foretaste of Adam Pownall’s new play entitled ‘*Getting Better Slowly*’, which has opened to “rave reviews”. At present all the advertised performances seem to be east of the Pennines, but hopefully it will come to the North West soon.

Not being familiar with Glasgow Fiona and I used Sunday to go on a bus tour of the city. Sadly the weather turned to rain so we covered inside rather than taking advantage of the open top bus and hopped on and off at the Transport Museum and Kelvingrove Museum, both very interesting. Finally back to the station for the train home after a very enjoyable weekend.

Gerald Wilson

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The next meeting will be our Christmas party; Saturday 3rd December 1.45 pm, there will be our usual Tortoise drive which gives rise to lots of fun. Then we are going to be entertained by Sybil’s friend Angela Mills, Angela is going to perform a rendition of Pam Ayres poems prior to a Jacobs Join banquet. There will be stalls with Christmas gifts, jewellery and Christmas garlands handmade by Sybil. You can pre order your Christmas garland beforehand by e mailing Sybil, (see page 4). Everyone welcome to our party.

Dates for next year 2017  
Bilsborrow Village Hall 1.45 pm

March 11th  
June 17<sup>th</sup> AGM  
September 9th  
December 7<sup>th</sup>

Speakers to be arranged

The committee and members of the Lancashire and Cumbria branch would like to wish James Babington Smith all the very best for the future having stepped down from his position as Chairman of the charity. James has visited us on several occasions, most recently being March this year.

The committee would like to thank everyone who attends our socials and support us, also thank you to those of you who have joined the 100 club.



We wish you all a Merry Christmas and a happy and healthy New Year



Contact details for the Lancashire and Cumbria Branch are;

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GAIN is a registered charity that offers support and information for those who are affected by Guillain Barré Syndrome, CIDP and associated inflammatory neuropathies.

For further information or support contact head office at the following;  
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