

**Summer 2016 Issue**

Our usual traditional Christmas party in December 2015 was a huge success. Despite storms that caused floods and devastated the North West and Cumbria, 27 attendees made it to the party. After a late start members



enjoyed some festive fun with the 'Tortoise Drive', followed by Sybil (chair) who gave a narration of '*Rinderella and her sugly isters*', she delivered it word perfect and had everyone laughing. Sybil did assure us she had only drunk a cup of tea!!!! Next was our questions and answer forum where we share our experiences, new members especially finding this very helpful. Tim had a surprise raffle prize all

wrapped up in a big box, to the delight of the winner, in addition to lots of other prizes. There was a fabulous array of food which members had brought and everyone tucked in with the opportunity for socializing.

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**March AGM**

Adverse weather again on the day before the Saturday meeting with inches of snow falling, it wasn't looking good for those travelling to Bilsborrow, but with a sigh of relief the weather improved overnight and most of it had gone. 26 attendees managed to make it including Doug who had travelled all the way from Newcastle to be with us.

Sybil, Chair, opened the AGM by giving a warm welcome to James Babington Smith. Jamie, who is Chairman of the national GAIN charity, had travelled all the way from Scotland to attend. After reading out apologies Sybil expressed her thanks to each individual committee member for all their hard work over the past year, adding '*What splendid teamwork of which I am immensely proud*'. She went on to thank members for their support and said how pleased to see attendance had increased reaching up to 35.



*Jamie and Sybil*

Joan, Treasurer, gave her report of the financial situation. She followed by thanking everyone for their effort in raising money for the branch funds. She thanked individuals, Sybil for her talented handiwork and sewing, the Christmas garlands she makes, and enough jam that would fill a shop shelf. She thanked Margaret and Peter for holding their garden party in the summer and the superb cards and gifts that Margaret makes. Also, thanks were expressed to Tim for the raffle and all the prizes, Glenis who runs the 100 club and sells jewellery, and Ann who sells footwear. Joan also thanked Rosie who in the past has raised monies by collecting ink cartridges for recycling, sadly, due to the revenues being low and collection costs rising it is no longer viable to continue. But Rosie is filling a bottle with 5p coins and she brought bottles of perfume to sell. Joan next thanked all members for their donations and raffle prizes and added it is their staunch support that makes the branch successful.

Rosie gave an update on '*Rosie's Project*' which is for the training of paediatric nurses treating children with GBS. She was pleased to announce a major step forward, working with Caroline at head office the academic leadership and

GAIN accreditation for the course was offered from a senior lecturer at the University of Cumbria. Rosie thanked Jamie for his support.

After the business part of the AGM had finished Sybil invited Jamie to address members. He started by saying the Lancashire and Cumbria branch is unique, in the fact it is the only formal branch of GAIN charity in the UK, having its own bank account and committee. The other local branches are now informal gatherings. He stated how pleased he was to see the enthusiasm from both the committee and members. Jamie went on to give an update on the charity, raising some interesting points. He said the charity is in good health. The amount of people wanting information has risen, but in today's changing society the main source of information is from our website. There are fewer and fewer referrals but the helpline has increased. He said the charity needs to review how data is stored, and how we have to maintain strict patient confidentiality. Various questions were asked and Jamie was very informative in his replies. One enquiry was on the Zika virus; it was commented that due to the Zika virus in the recent news Guillain Barré Syndrome was getting much needed publicity and awareness.



Finally, Jamie invited members to the 2016 'gain2gether' conference in Glasgow on Saturday 25<sup>th</sup> June, to be held in Glasgow University, there will be world renowned speakers and leading neurologists addressing the conference. He added there would be details shortly about the arrangements for a dinner in the evening whereby speakers, and friends could get-together and socialize, thus making a good weekend by staying over.



It was brought to Jamie's attention about the new regulations that may affect volunteers visiting and supporting patients in hospital wards at The Royal Preston Hospital. It is now required that charities have to be registered at the hospital with strict guidelines for patient confidentiality. Occupational Health Risk checks, blood tests, insurance etc. etc. have to be complete and the list goes on. Jamie advised that we get the paperwork in place and send it to the group for their attention. (In view of this the office is now looking into this and they are hoping to confirm the situation soon).

Our regular member Chantel, who attends with boyfriend David and mum Anita, gave us a very moving talk about her GBS recovery and her experience of the physical and psychological side of it. But firstly she gave some feedback from points made at the Charity's York regional meeting, points of which she could relate to. She elaborated on her time in hospital through to how her life has changed, for the better, and how she is managing uncertainties that she is presented with. Chantal is an inspiring and beautiful young lady and although 'Mother's Day' was only a few hours away we are sure mum Anita was the proudest mother that day. Comments afterwards were 'spellbound', 'very moving', 'heart rending'.



During a conversation with Gill and Caroline at head office and in addition to a lovely spell of warm weather it was suggested by Caroline (Director of GAIN) that the information below would be quite useful now the summer is just around the corner. Caroline has used this service elsewhere herself and said it works really well.

## **Fancy a day out in Lancashire and Cumbria**

Need to use a wheelchair or mobility scooter?  
 Feel you can no longer go hiking in the countryside?

### Think again - think Trampler



The Trampler is a specially designed four wheel drive all-terrain electric buggy which can be used off road and even on rough ground, mud and grass. It enables people who have difficulty walking to experience the countryside, woodlands and lakesides; and to accompany their friends and families when out walking.

#### Trampers are available for hire from:

- Beacon Fell Country Park, nr Scorton 01772 534709
- Wyre Estuary Country Park, Thornton 01253 857890
- Witton Country Park, Blackburn. 01254 55423
- Wycoller Country Park, near Colne 01772 534709
- Beacon Country Park, Up Holland, West Lancashire 01695 622794
- Forest of Bowland
- South Walney Nature Reserve, Barrow in Furness 01229 471066
- Sizergh Castle, Sizergh near Kendal (National Trust)
- Tarn Hows, Boon Crag, Coniston 01539 441456

You will need to book ahead to ensure that a Trampler is available.

More details about Trampler and accessible places can be found on the internet. Here are few suggestions:-

[www.disabledramblers.co.uk](http://www.disabledramblers.co.uk)

[www.trampler.co.uk](http://www.trampler.co.uk)

[www.visitlancashire.co.uk](http://www.visitlancashire.co.uk)

[www.nationalparks.gov.uk](http://www.nationalparks.gov.uk)

[www.accessiblecountryside.org.uk](http://www.accessiblecountryside.org.uk)

[www.nationaltrust.org.uk](http://www.nationaltrust.org.uk)

The dates for the remaining meetings this year are as follows;

Bilsborrow Village Hall, 1.45pm

- ❖ June 18th.....Plant sale and demonstration
- ❖ September 24th.....Speaker - Jacqui Hughes  
*Keeping Children Safe – Preventing Radicalisation*
- ❖ December 3rd.....Christmas Party

Our regular member Jacqui Hughes will be giving a talk at the September meeting, her subject will be - *Keeping children safe-Preventing Radicalisation*, this is not to be missed and knowing Jacqui it will be very interesting, everyone is welcome.

Contact details for the Lancashire and Cumbria Branch are;

Sybil Loxam, Chair. [sybilloxam152@gmail.com](mailto:sybilloxam152@gmail.com)

Gerald Wilson, Secretary. [GWilson404@aol.com](mailto:GWilson404@aol.com)

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:

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

Tel: 01529 469910

Helpline: 080 0374 803

Email: [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk)

Web: [www.gaincharity.org.uk](http://www.gaincharity.org.uk)