

**SUMMER ISSUE 2015 NEWSLETTER**

**D**ecember 2014 meeting included our usual Christmas party; it was a huge success with 31 attendees. Sybil (Chair) welcomed everyone and gave a special welcome to the six new attendees who came, Karrie and her mum Vicky, Adele and her partner Mike with their lovely little girl Kyrie, and Gerald's friends David and Enid. Next we held the usual dice throwing game 'Tortoise drive', this created lots of laughter and some of the funniest drawings of a tortoise. And Santa gave a festive feel to the event.



After the games we held the question and answer forum, this again was found to be valuable especially with the new members. At each meeting the forum tends to lean more to one subject unintentionally, and this time most of the discussion was not being able to cope with cold water as in a normal swimming pool. Jackie suggested a hydrotherapy pool would be more suitable as the temperature was much warmer. And again throat problems after GBS/CIDP was discussed and seems to be common within our branch

Glenis organized the 100 club and Tim followed with the raffle and lots of prizes. There was homemade Jam and garlands for sale, made by Sybil, and Glenis brought some jewellery for sale.

Members tucked into the Jacob's Join food which members had brought, it was truly delicious. Thanks to Colin who provided the tea and coffee. We had celebration cakes brought by Chantel and her mum, it was Chantels 30th birthday and she was looking forward to celebrating with friends.



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**T**he first meeting of 2015 was the branch AGM presided by our chair Sybil. To begin Sybil opened with a warm greeting to those present and said how good it was to see so many people attend. Also a warm welcome was given to Russell B Hamilton and his wife Karen who had travelled all the way from Peterborough to be at our AGM; Russell is one of the Guillain-Barre & Associated Inflammatory Neuropathies (GAIN) charity trustees. Sybil welcomed the new attendees, Jean from Rossendale, Ken from Bury, Mr Clapham from Bolton, and also the return visit of Mr and Mrs Ford. She gave a brief account of the activities over the last twelve months and thanked the committee individually for their duties and the hard work they had carried out throughout the year.

Joan next presented the accounts; she explained how the changes to the branch year end had to be in line with head office. Joan thanked Tim for the excellent raffles and for the leg wax earlier in the year, she also thanked Glenis who has taken over the 100 club and brings in a steady income, Sybil for her art and crafts and the Jam she makes and sells, Rosie for collecting ink cartridges, Peter and Margaret for their coffee morning that they hold every year, and anyone else not mentioned but who had supported our cause.

Rosie gave an update on 'Rosie's Project' and how it is progressing. She explained that due to such a lack of information for children with GBS and support for their families she is in the process of talks with the possibility of a training course for paediatric neuromuscular nurses and perhaps the production of an information DVD to help families. Rosie has continually worked hard following all avenues and speaking to several professionals, whilst taking part in discussions with Paediatric Consultants and Specialists, including a professional Development Sister in Neurosciences for input.





Under any other business - GAIN Trustee Russell B.Hamilton addressed the meeting by making a number of observations about The Lancashire and Cumbria Branch. He said he was pleased to be able to attend the meeting with his wife Karen, and thanked all branch members for their welcome and all they do. He went on to say that it was fantastic to see such great enthusiasm within the group and good to see the branch engaged in such a wide range of activities that were so clearly well supported and raised a lot of money for the charity. Russell also said that it was particularly pleasing to see such a good cross section of age groups at the meeting as this is important for its future. He then complimented the branch on the quality and content of its regular newsletter. In conclusion Russell said he was impressed and thanked the branch from both himself and across the board, adding that he hoped to see members again at a future meeting.

Following the formal business of the AGM meeting Sybil introduced our speaker, Mr Geoff Wood who gave a talk about 'The Life and Times of a Sewer Rat'. Geoff started his humorous and informative talk by saying he had spent all his working life in a sewer and what a fascinating job it was. He was the regional 'Waste Water network operations Manager' covering all the sewer systems from Crew to Carlisle. He gave a funny insight of sewage throughout history, how in medieval towns chamber pots were emptied directly in the streets, he reminded us of 'The great stink' in the summer of 1858 in London. His talk was so interesting and at times funny he had members laughing on several occasions throughout.

Colin served tea and coffee and an array of delicious cakes made by members, Tim organised the raffle, and then Glenis followed with the 100 club. Next we had a questions and answer forum before retiring for home.

We would like to thank Jo, Margaret, Audrey and Fiona for their help on the day, it was much appreciated and helps the event to run smoothly.

*The committee would like to express our thanks to Sybil, Chair of the branch, for the amount of hard work she does to keep the Lancashire and Cumbria branch running so smoothly. She's like a swan floating serenely on the pond with its feet working like mad under the surface. We know how much it takes to achieve what she does and what a struggle it sometimes can be to achieve it – and this year must have been so much more difficult without her beloved George. So this is an even bigger reason for us to thank you, Sybil, just for being there for us all.*

Since the meeting we have had some great feedback comments from the new attendees who found the meeting friendly and interesting, they said it was good to meet and chat to other people about their condition and ongoing residual symptoms, adding that it was good to know they were not the only one suffering GBS and were pleased to know support was there if needed. One attendee was grateful to Jo for the good advice on her feet. The committee are delighted with such comments and we hope to see you all again at our future meetings. Dates printed at the end.



At our last meeting we were intrigued about the ‘support wrap’ that Mike was wearing on his foot and leg, he gave us a demonstration and explained how beneficial it is for him especially when he goes running. Mike has kindly shared this information as it may be of interest others who have dropped foot resulting from residual symptoms.

### **THE FOOT-UP AS AN AID TO FOOT-DROP SUFFERERS**

At the age of forty eight in 1988, I suffered from a severe bout of GBS that resulted in total paralysis, six weeks in ICU and a prolonged recovery. This left me about 90% recovered; I never fully regained use of my hands, legs, feet and some facial muscles’. In 1997, by chance, I discovered I could run much more easily and much further than I could walk, (you don’t need as much foot flexion when you run). Since then I’ve covered an enormous number of miles –twelve and a half thousand to be precise, as I logged every one, nerd that I am!



About eighteen months ago I had to give up running altogether when my foot-drop became more pronounced and I kept tripping up – always with my left foot hitting barely noticeable protrusions. Then I discovered the ‘foot-up’ – a simple device that consists of a Velcro upper that wraps around the ankle and is firmly attached to a plastic counterpart anchored to the shoe-laces. It is easy to fit the anchor in the shoe where it stays permanently, and to attach and detach the upper takes no more than five seconds. In short, the device allows me to run without tripping and it also gives me support when I walk.

When Professor Jim Richards of the University College of Central Lancashire (UCLAN) in Preston, and expert in orthotics and ‘movement’, gave a talk and demonstration to our Saturday social group in 2013 he was interested in the device. When he checked he discovered that no research had been done on its efficacy. So he invited me to attend his workshop to see how it works and what effect it was having on me. The top and bottom is that, with the help of his assistant, Jessica Jansson, Jim put me through my aces both walking and running, with and without the device, while measuring my body movement ‘digitally’ and ‘graphically’. The conclusion in lay language (the language he uses for his study, which has to be approved by his peers, is highly technical), *“the foot-up supports you slightly better when walking than when running – some differences were found in your quadriceps muscles – at the front of your upper leg - and the ankle muscles, between walking and running”* The foot-up has also made a difference to my posture in the pelvis area. Although I haven’t noticed any of these changes, the important thing for me is, by improving its flexion; the foot-up raises my left foot by about a millimetre which is just enough to stop me tripping while running.

It was interesting to see Jim’s workshop which is a large gym that has an array of equipment, both mechanical and digital. The electronic gadgetry was particularly impressive and I had a strange experience of seeing my skeleton in motion.

The message is, if you suffer from foot-drop and you want to walk or even run more efficiently, give the foot-up a try. However, please remember, if you are taking exercise after a prolonged period of immobility, be sure to discuss it with your doctor, and start in very easy stages.

The manufacturer is ÖSSUR (see their webpage or phone: 08450 065 065), the basic cost is just over £50, and extra inserts at £15 each; you’ll need about three of these depending on how many shoes you regularly use. The foot-up comes in black or beige and it comes in three sizes – medium, large and extra large – I take size nine shoes, so a large one fits me.

Mike.



To those of you who attend our social meetings regularly, you will remember Sybil's husband George Loxam, who sadly passed away last year. George had many qualities and was highly respected at the branch and by committee members, always at Sybil's side supporting her. Sybil often talks about George and how much she misses him, the little things she wants to tell him, she said how lonely it is without him and her bed socks don't make up for him!!!! Here are a few thoughts Sybil would like to share.

### 'Life after George'

*I do miss him, and not only his physical presence, his support and love....this coming from the female who, when taking her two young children in the car alone to Manchester to visit her parents, was advised by her father before setting off to check the water and oil levels, and who phoned her father back complaining that she couldn't pour the oil down the tiny hole where the dipstick had come from! Instead of George and I spending many happy times playing Scrabble, doing crosswords, holidays abroad, projects in the garden, jazz concerts, dog walking etc, maybe we should have spent time with him showing me how to wire a plug, use an electric drill, fit light bulbs in awkward lamps, replace fuses, check tyre pressure etc, the list is endless. I found what appeared to be a 'saucer-sized giant tarantula' glaring at me from the bottom of the bath – no St George to rescue the damsel in distress – instead I had to get my own piece of card, a glass and a pre-opened window to deal with the monster. Three dead mice one after each other, pinioned themselves to the mousetrap in the loft and there was no George to gallantly deal with them whilst I beat a hasty retreat, so I had no choice but to remove them and reset the trap, after having a friend show me how to do it. Then where did he keep his alun (is that spelt correctly) keys, the new fuses, the jigsaw blades, starters for the fluorescent lights, etc, and how do I fit them when I find them? Every day brings a new problem, a new challenge – I am sure he is up there sending these problems down and laughing.*



*Being a true Yorkshire man, down to earth and not given to flowery words, he didn't exactly get down on one knee and ask me to marry him. His proposal was in the form of 'Are you prepared to give up your independence?' and I thought I hadn't but I must have done! He'll be watching and chuckling at my attempts to do the things he always did and the things I took for granted.*

*SO, just take heed all you happily married couples reading this and think on, maybe a month or three of role reversal should be compulsory. Who deals with the banking, the bills etc. And who does the cooking, who sorts out the car MOT, tax and repairs, who changes the bedding and does the washing, I could go on and on. I was a brownie, a girl guide and a wolf cub officer but unfortunately, I apparently never followed the motto of 'BE PREPARED'.*  
Sybil.

### **2015 MEETINGS – 2.00pm – BILSBORROW VILLAGE HALL, BILSBORROW**

JUNE 6<sup>th</sup> ..... PLANT SALE, ACCUPUNCTURE - VOLUNTEERS WANTED

SEPTEMBER 26<sup>th</sup> ..... PROGRAM TO BE ARRANGED

DECEMBER 5<sup>th</sup> ..... CHRISTMAS PARTY, JACOBS JOIN

Contact details for the Lancashire and Cumbria Branch are;

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**Guillain-Barré & Association Inflammatory Neuropathies** 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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