

Winter issue 2016

June meeting was another great success with 35 attendees, Sybil our chair welcomed everyone especially those who visited for the first time. A special welcome was given to Sam Jones who is a Neuromuscular Specialist Nurse at The Preston Royal Hospital, Preston, where several of our members receive their treatment by Sam, she said she was delighted to visit us again and see so many familiar faces. After an interesting and informative talk on acupuncture we came to our forum where we exchange experiences and discuss residual symptoms. Prickly tongues and Botox for facial palsy was discussed, a lot of people had experienced problems with the skin on their feet, including very dry skin, peeling and 'scales like a crocodile' which just dropped off in large pieces. Tim followed with the raffle and lots of prizes and Glenis drew the 100 club. We had an overflowing plant stall and Sybil sold her delicious homemade preserves. Ann and Colin provided tea and coffee and homemade cakes, Joan made scones which she filled with fresh cream and strawberries, all of which were delicious.



On the 20th June, Gerald and his wife Fiona attended the GAIN AGM and Regional Day at Peterborough, they said they found it very interesting and had lots of chats with people during the breaks. The following day they visited the cathedral which they thoroughly enjoyed. There is a report of the day in the summer issue of 'Gain4all' magazine.

Colin and Ann Birchall, who are both on the committee, celebrated their Golden Wedding on June 12th, committee members collected and bought them a David Austin rose bush and presented it at committee meeting. Ann had GBS in 1998 and both have been members of the Lancashire and Cumbria branch since 1999, and Ann produces this newsletter.



On behalf of the committee and members of the branch we would like to express our heartfelt thanks to Peter and Margaret Sandiford for their generous donation from their garden party event they held in the summer, a huge thank you for their effort in making it a great success.

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One of our members is a young lady in her early twenties, Karrie Luchia Houghton, who was diagnosed with Guillain Barré Syndrome in 2013. Karrie was and still is a very active person who loves climbing mountains, running and ice skating, in addition to taking on many challenges which has raised money for gain and other charities. We at the branch are so proud of Karrie and all she has achieved, she is an inspiration. Here is Karrie's experience of GBS in her own words.....

My name is Karrie and I'm a 22 year old Mental Health nursing student. In November 2013 I started to feel unwell and began to develop symptoms of GBS, I was admitted to hospital and became paralysed from the chest downwards. Initially I wasn't too worried about my course as I thought I wouldn't miss too much and would soon be back. When I read up on the illness and what GBS was about I did panic about finishing my studies. A nursing degree is 3 years long but has to be completed in 5 years, if not you cannot qualify and have to redo the whole course. After discovering the recovery could take 12 months or even years I was upset at the thought that I might not get well enough to return. However the university were incredibly supportive and my Mum reassured me that we'd do everything we could to get me back to university and encouraged me to take just one day at a time. I had to have an NG (nano-gastric) tube fitted, it is a tube that is inserted through the nose and



into your stomach, the nurses can then use this to put medication and liquid food down. I also had a pacemaker to control my heart rate.

Eventually I began to improve with amazing support from my family and the hospital staff. I received intensive physiotherapy and was encouraged to write a list of short and long-term goals. One of my early targets was; being able to get into a wheelchair and go home for a few hours on Christmas day. Whilst my long-term goals were: getting back to my ice skating and entering competitions, running a 10km race and returning back to studying for my degree. I did manage to go home for Christmas! Despite my neurologist telling me it would be unrealistic I managed to transfer from the bed to a wheelchair with the use of a board, this meant that the physiotherapist was happy for me to go home for the day. My Granddad picked me up in the morning and I spent the whole day at home before returning to the hospital in the evening. I was utterly exhausted but had such a lovely day with family it was all worth it.



Before I became ill with GBS I was a very fit and active person; I loved running and particularly enjoyed figure skating, so I was determined to return to these activities. I was discharged in January 2014 and spent the next few months doing daily exercises to slowly build up my strength.

In July 2014 I finally had the pacemaker that was fitted removed, this was a big step forward and I decided at this point to do a year long series of sporting events to raise money for GAIN and also the MS Society. I wanted to see how far I could push my body to prove to myself that GBS won't ever prevent me from attempting anything in my life. I do still have residual nerve pain but for the most part I am fully recovered and look forward to more challenges.

So far I have done: the Preston 10km run; a Boxing Day 10 km run (which was very cold); the Great Manchester Run; walked up Ben Nevis and now I'm training for the Great North Run in September. Walking up Ben Nevis was a really very difficult challenge for me but I was lucky that my mum, Auntie and boyfriend all joined me for that climb and encouraged me on. I think the Great North Run (which is half a marathon) is really going to test my fitness but I'm really anticipating the challenge.

Finally, in June 2015 I competed in the British Adult Skating Championships and came 3rd in my category. I am so happy that I could return to skating and really think that continuing to skate has helped my recovery!

I managed to return to my course work a year after I contracted Guillain Barré Syndrome, I settled back in really well and everyone has been so supportive. I've now just finished my second year with good results, and am looking forward to the future.

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September meeting was well attended with 33 members, including 2 new attendees. Sybil firstly welcomed everyone and then introduced our speaker Julie who is a volunteer for 'Hearing dogs for the deaf', Julie brought her dog Sky and gave a very interesting and at times funny insight into her role as a volunteer. Hearing dogs are specially trained to assist people who are deaf by alerting their partners to the common sounds around the home such as the door bell or telephone ringing, alarm clock or a child's cry, the dog will 'touch and tell' alerting their partner to a sound and lead them to the source, if the alert is dangerous, say a fire alarm, the dog will lie down. Julie explained the family have to be trained also and if the doorbell rings they don't answer as that is what the dog is trained to do.



Julie's dog Sky is 12 years old and Julie has had her for nine years, in that time they have formed a great partnership, going everywhere and doing lots of things together, she is a real character. As Julie explained a hearing disability is invisible and Sky has boosted her confidence. She is trained to 'touch and tell' using her paw; new dogs are now trained to 'touch with their nose'. Sky has to be assessed every twelve months to make sure she is fit and healthy and her weight has to be 25 kilograms. The dogs have to retire at eleven years onward but be retired by the time they reach thirteen. Julie had everyone laughing at the funny incidents that she has experienced while out and about, shopping or giving talks in schools.

Next we had our usual forum where we discuss residual symptoms and exchange our experiences. This time it was the throat that was discussed; several individuals said they had problems whereby they couldn't sing following GBS. Regular member Chantel has Bilateral vocal cord palsy, (paralysed vocal cord) she has had a few operations on her throat and gave us an update after her recent operation, she now has a speaking valve which is an improvement but she still has a long way to go.

Gerald gave feedback on GAIN AGM & Regional day in Peterborough while the tea, coffee and cakes were served, Tim followed with the raffle.

Margaret Sandiford had a stall full of her handmade cards and beautiful handmade gifts for sale, her work is very talented.



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Regular members Doris Stewart and best friend Jacqui Hughes have been coming to the branch meetings since 2010. When Doris became ill with Guillain-Barré Syndrome Jacqui was not only her friend, she became her carer. It was suggested Jacqui put pen to paper and she came up with writing something a little different, **Guillain Barré - Syndrome from a carer's point of view**, with a twist. After Jacqui had finished her piece, she said she hadn't realised the impact reliving the events would have. Carers of loved ones are on an emotional journey too, and Jacqui has put together that journey superbly.

My name is Jacqui and I have been asked to share my experience of supporting my best friend through the journey from diagnosis to recovery from Guillain- Barré Syndrome. Before you begin to read this account, two things need to be made crystal clear. Firstly, I am 'as mad as a hatter', a born optimist and always see life as 'a glass half full'. Secondly, I love music and always associate events and moments in time with lines from famous songs. So, I challenge you to identify all the songs referred to in this reminiscence!

"Where do I begin to tell the story?" – Well 7 years ago my life was quite normal (normal for me any way!!!!). I had a job that required me to create 26 hours in every day – but they were "Happy Days". I loved my job and I really loved my social life with my best friend Doris. Doris had unlimited energy and she did everything at double speed. I frequently found myself 'Power Walking' – well "Keep on Running, Running From Now On" just to keep up with her!



JACQUI

In fact I nicknamed her as Speedy Gonzales!!!! The winter of 2009 was colder than normal, but Doris and I still faced "Stormy Weather" to take my Boxer dogs on long walks past "Mountain High and River Deep". The truth was that my dogs followed 'Auntie Doris' like the Pied Piper – I just trailed behind! I was constantly in awe of Doris's energy and the way she "Talked with the Animals" (the truth is she prefers dogs, cats, degus, and parrots etc. to humans – she often says 'animals give love that is unconditional'). All the indications were that it was going to be a "White, White Christmas". Little did I know it was going to be a "Blue, Blue, Blue Christmas" before very long!

As usual, her daughter and granddaughters came up from Dorset for Christmas and we all had a great time, including time with her other daughter, son-in-law and grown up grandsons. I did, however, notice that Doris was very tired and frequently began to complain about feeling ill and having tingling in her mouth and feet. After the family had all gone home, the symptoms became worse and on 31st December she finally agreed to ring the doctors. Well what a waste of time!!!! She could not get an appointment and even worse the receptionist decided to advise 'It is just a chill – take paracetamol and keep warm'. When Doris pointed out she has an allergic reaction to paracetamol and they make her sick, the receptionist replied 'Well never mind – you will just have to be sick!!! (Needless to say, when Doris ultimately ended up in hospital, I started the "Battle of Jericho" and the "Walls Came Tumbling Down". I loudly and publicly tore a strip off the receptionist, practice manager and senior doctor at the

practice and Doris eventually received an unconditional apology and assurances that new protocol would be put in place to prevent receptionists giving medical advice). Over the next few days her symptoms got worse. After the asinine response from the Surgery, she refused to contact the practice again. Eventually, during the following weekend, I dragged her to the Emergency Doctors and she saw a recently qualified doctor who examined her and commented 'If it wasn't so rare, I would suspect you could have Guillain- Barré Syndrome. If the symptoms persist or go worse you must go to Accident and Emergency'. Less than 48 hours later the symptoms were significantly worse and I ended up taking her to A&E. After 6hrs in A&E they decided she had a Renal Infection, sent her home with medication and told her to contact her GP for an appointment within the next 2 days. The next day I went off to work and rang Doris every couple of hours to check how she was and whether she had got an appointment at the doctors. She had managed to get an appointment, but not for 2 days. I visited that evening and became very concerned; she looked really poorly and was very unsteady on her feet. Against my better judgement, I went to work the next morning and just hoped she was going to be OK till I could take her to the doctors. Oh boy! Did I have a day to remember!! Around 3pm I got a phone call from Doris's doctor who was actually at Doris's house, her legs had lost all feeling and the doctor had found her crawling to answer the door when she arrived! The doctor had arranged admission to hospital but it was going to be up to 3hrs before an ambulance could attend. The doctor asked if I could come home and take her to the hospital as it would be quicker than waiting for the Ambulance. I picked up my briefcase and was "Homeward Bound" within 5 minutes. I got to Doris's house and the doctor helped me get Doris into the car – I set off and the doctor rang the hospital to confirm we were on our way. We were met at A&E and Doris was quickly transferred into the Observation Ward. After 4hrs I was told she was settled on the ward and I should go home and ring in the morning. It was now 9pm, so I went home and contacted Doris's eldest daughter (who lives 8 miles away) and agreed we would ring the hospital the next morning then meet at visiting time the next evening. The next morning I rang and was told she had 'a comfortable night' and they would have carried out tests to identify what was going on by visiting time that evening. Little did I know that was "Castles in the Sky"

At around 11 o'clock that morning I received a phone call from Doris's daughter asking me to get to the hospital as quick as possible. Doris had deteriorated rapidly and they were going to perform a tracheotomy. However, Doris being Doris, she had refused to let them perform the procedure till she had spoken to us both! I picked up my car keys and flew! It is true to say I was driving close to the legal speed limits but was clearly "Flying without Wings". Her daughter and I arrived within minutes of each other to discover she was paralysed up to her mouth, but refused intubation until she had seen us both. Listening to my best friend (and partner in crime) trying to tell us both "Time to say Goodbye" was heart-breaking – but I needed to be strong for her daughter. Once that ordeal was completed, Doris was taken into Theatre and we sat and waited for news. Following the operation, the surgeon came to talk to us and told us it was definitely 'Guillain-Barré Syndrome' and that because of Doris's age (66) and a history of COPD, recovery was going to be very slow and it was unlikely she would ever live independently again! Realistic as this may have been – they underestimated the "I Get knocked Down and I Get Up Again" attitude that is Doris!!

I had previously seen people in Intensive Care so warned Doris's daughter to expect her mum to look 'rough' – OMG! I was not prepared for the scene before me – the lighting in the side room was dimmed and there were numerous



Jacqui and her friend Doris

tubes and machines attached to Doris. It was a cross between "Ground Control to Major Tom" and "I'm an Alien, I'm a Legal Alien". Having recovered from the initial shock, her daughter and I settled into a pattern that would carry on when we visited over the next 7 days. Doris drifted in and out of consciousness and we sat and shared funny stories about the person we both knew was the real Doris. There were serious concerns about Doris's lung function and the complication of a chest infection. The ward staffs were really good. They constantly monitored the tracheotomy and cleared blockages, cared for her with compassion and reassured

us both she was going to improve soon. They were right – within 7 days she had improved enough to move to the Intensive Care Ward and was much more alert. In fact, she started trying to talk and this presented a situation that verged on a comedy routine. Her mouth didn't move properly and the tracheotomy meant there was no sound!!! Doris got really cross with us because we could not

understand her – the solution was akin to a game of ‘Charades’. All I could hear in my head was “Give Me a Sign. Hit Me Babe One More Time”.

During the next couple of weeks the chest infection was improving, but did cause repeated blockages in the tracheotomy, which caused Doris considerable distress and fear (she still couldn’t speak and therefore became terrified she could not let them know when it got blocked). To address this, staff made a makeshift rattle, using a small sample bottle and bits of plastic, and fastened it to Doris’s wrist. All she had to do was shake the rattle if she needed help. Well – it was a roaring success and whenever she rattled, it was reminiscent of the Dowager at Downtown Abbey!!! At this point, two significant things happened. Firstly, following a period of gradual independent breathing, the tracheotomy was finally removed and secondly, they found Doris had contacted MRSA. The treatment was a regular application of a body wash – the only problem was that she had an allergic reaction and her skin went bright red. She looked sunburnt and all I could think was “Last Year We Went to Sunny Spain”. However, she was now off tube feeding and eating real food! The only problem was that the liquidised food served at mealtimes was ‘gross’ – I decided the best answer was to make rice puddings, soups and liquidised stews at home and bring them in each day in a food thermos.

The skin reaction subsided and the next 2 weeks of the physiotherapy sessions finally gave Doris the strength to start walking. I would like to say it was “Wheels on Fire” but initially it was more “Only 24hrs from Tulsa” – but it was independent mobility!!!! Within a week or so she finally transferred to the High Dependency Unit where she continued to make slow but steady progress and very quickly moved to the Rehabilitation Ward. She had turned a corner and it was a case of “I Can See the Green, Green, Grass of Home”. It was now the end of April and it was all systems go for a weekend ‘pass’, prior to planning discharge. There was a suspicion she had picked up an e-coli infection, but the hospital decided it was clear and Doris came to stay with me for her first weekend out of hospital in over 4 months. Well, 24hrs later she was running a fever and I had to take her back. I was gutted – but these setbacks are to be expected. I went home and was asleep before my head hit the pillow. Some hours later the phone rang and I “Woke up One Morning Half Asleep. With All My Blankets In A Heap”. It was 3am and Doris wanted me to take her an electric blanket cos she was freezing. I thought she was ‘off her trolley’ but the nurse came on the phone and said it was OK, the e-coli infection was causing the shivers and gave me instructions on how to get through the hospital to the ward. To fully understand this fiasco you need to know two things. Firstly I am terrified of the dark and secondly, to get to the ward out of hours, you have to go via the Morgue! With electric blanket and Imodium in hand it was like “The Monster Mash” but I completed my mission!

The infection cleared and two weeks later Doris was discharged to my care (much to the horror of Doris’s daughter – she believed I was too irresponsible to care for her, but I have a bungalow, so it was a ‘no brainer’). Doris stayed with me for the next 3 months while she recovered her strength. There were times she became very upset that she was not making the progress. But she still fought and “The Higher You Build Your Barriers, The Taller I Become” reflects her determination. Between hospital appointments and clinics she began to make rapid progress and had a phased return to her own house. When I finally moved her back home I knew it was important to let her have her space and independence but couldn’t help saying ‘You Just Call Out My Name and I’ll be There’. It was so hard to walk away – but it was the right time. The first time she got behind the wheel of her car and actually drove again, I knew she had won the battle.

*Over the last 6 years, she has gone from strength to strength. As expected, there have been many frustrations and hard times but throughout she “Ate It Up and Spat It Out”. She still has some weakness in her legs (she sometimes wobbles when walking and often refers to it as doing the ‘Viennese Waltz’) but I have my best friend back. Her wicked humour and mission to control my ‘sweet tooth’ is as sharp as ever – and I couldn’t be happier!!! I am no longer the Carer – **now I just care deeply**. I watch her take off in **Kermit** (her new yellow Nissan Juke) and I feel so proud of how far she has come.*

I hope this article is helpful for those Carers who have “Only Just Begun” the journey and those who are still on the “Long and Winding Road” to seeing their loved one beat Guillain-Barré Syndrome. For me it has been a privilege to

take that journey with Doris. My thanks go to all the members of Lancashire and Cumbria GAIN support group at Bilsborrow, their friendship has been invaluable.

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The committee would like to thank all the article contributors who have been willing to share their story in this newsletter; it helps others to know they are not on their own. And remember each person’s journey is unique.

Has anyone any spare wooden coat hangers needed for a project for Sybil, please could you bring them to the next meeting, thank you?

Reminder

Enclosed with this newsletter are the 100 club forms, subscriptions are now due. We would welcome anyone wishing to join.

The committee wish to thank members of the branch who help with washing up, tiding the room etc. at the meetings, it is a great help and very much appreciated.

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DATES FOR NEXT YEAR

<u>2016 meetings – 2.00pm – Bilsborrow Village Hall, Bilsborrow</u>	
<u>MARCH 5TH</u>	AGM
<u>JUNE 18TH</u>	Plant sale, speaker
<u>SEPTEMBER 10TH</u>	Program to be arranged
<u>DECEMBER 3RD</u>	Christmas Party, Jacobs Join

Everyone welcome

Contact details for the Lancashire and Cumbria Branch are;

Sybil Loxam, Chair. sybilloxam152@gmail.com Gerald Wilson, Secretary. GWilson404@aol.com

The support group 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: 0800 374 803 Email: office@gaincharity.org.uk Web: gaincharity.org.uk

On behalf of the committee, we wish you all a Merry Christmas and a healthy New Year,

