

SUMMER / AUTUMN 2018 NEWSLETTER



Saturday 16th June brought forth a sunny and warm day, we were thankful for the good weather as it was the branch AGM and annual plant sale; our guests on the day were Caroline Morrice, GAIN Chief Executive, and speaker Dennis Moore.

Before our guests and members arrive, the seating and various stalls are arranged and the kettle, tea and coffee pots and cups primed, along with an array of savoury items, cakes and strawberry scones that were plated in readiness for serving later. We are very fortunate to have such delicious delicacies at all of our meetings and we are so grateful to those people who bring the items along.

After warmly welcoming everyone, Sybil our Chair, began her annual resume by saying how pleased she was with the successful year the branch had seen, adding how more attendees are coming to the meetings. However, it was hoped that this increase was due to people becoming aware of the existence of the branch, rather than an increase in GBS. Following on, Sybil paid tribute to the committee by saying each of them were loyal, dedicated, efficient and dependable, before adding a few individual words about each of them. We have two new officers on the committee, Ann Pennington, who has taken on the role of Branch Secretary and Michael (Mike) Hunt, who holds the position of Minute Secretary.

Unfortunately, our Treasurer Joan Haresign was unable to be with us; because of this Joan's report was given by Mike Hunt. This covered the financial status of the branch and praised the work of the committee and the unstinting support of everyone who attends our meetings.

Following on Rosie gave an update on 'Rosie's Project' by covering the meetings she has attended at the University of Cumbria, Lancaster along with Caroline Morrice who took part via speaker phone. Explaining that a critical stage had been reached in negotiations and a quote for the work was expected soon. Rosie explained how the university had expressed great interest in developing a group of three, ten minute episodes, covering onset and diagnosis, treatment and recovery; it is thought these two would be focussed on initially, with a third episode concentrating on rehab, physio and aftercare being added at a later date. On completion they will form part of the university's multimedia virtual training community 'Stilwell'. Rosie then handed over to Caroline for her input on the third episode and news involving the project, branch and GAIN.

Picking up the trail from Rosie, Caroline gave details of a small study into gait analysis and how volunteers would be required. However, ethics approval has had to be applied for and it is expected it may take six to nine months before recruitment can begin. Anyone in the Manchester area interested in taking part is advised to keep an eye on the GAIN website and / or social media. We were all interested, as Caroline explained her role at head office and how the charity has evolved since its conception, adding that soon the charity will have new headquarters, which on completion would be named 'Glennys Sanders House' in honour of the charity's founder. Focus then went onto the new range of GAIN tortoise gifts and other items available via the website and at branch meetings to purchase; particular attention was given to 'Moxie' the tortoise, who holds the very important role of the charity mascot - explaining how he was given his name after finding the description to mean 'grit and determination'....this is a true reflection of what is needed on a GBS sufferers journey.

Everyone found the topics covered by Caroline to be informative and interesting, it is always pleasing to receive updates from GAIN head office, no matter how small or large they are, they are always very well received and worthy of our attention. The meeting continued with Sybil introducing Dennis Moore, who gave a humorous talk titled 'Laughter is the Best Medicine'. We were given an explanation on how he sources material from various places, on recounting a range of funny stories and observations we were kept smiling from beginning to end.

Following on, we had time for a Q&A session that gave the chance for questions to be raised covering areas such as gait, pain relief, useful appliances and other areas of concern.

WE MUST UNDERLINE THAT ALL RESPONSES GIVEN DURING THE Q&A ARE ONLY OPINIONS AND GIVEN ON PERSONAL EXPERIENCE ONLY, AND ADVISE CONSULTING YOUR GP / CONSULTANT FOR ALL MEDICAL RELATED QUERIES

As usual, following on from the Q&A session, we were fortunate to have a variety of homemade sweet and savoury items to tuck into while the raffle and the 100 Club numbers were drawn.

At the request of newsletter editor Rosie, Sybil asked members for contributions - these can be in the form of personal recollections, poetry, interesting and inspiring stories or anything which would fit in with the newsletter and our members. Please send contributions to Rosie's email: rosemarieh@gaincharity.org.uk



After a very lovely summer, which we hope you all enjoyed, the September meeting was slightly different in format to our usual ones - the committee was decided that we would forgo having a speaker and instead have a 'getting to know you' session. We began with John Haresign, husband of branch Treasurer Joan who gave a very animated and accurate account of his journey from being diagnosed with GBS and followed through to recovery and rehab, and on to him returning home. Throughout the session, other members asked questions and

interjected with their own experiences and stories that highlighted the fact that GBS is not the same for everyone affected by it. Experiences of physiotherapy also differed, and it became apparent that there are no set rules for the application of this, as it can vary from hospital to hospital as well as areas. The session was very well received by everyone and continued during refreshments. It was interesting to hear how much those attending were encouraged by hearing the stories of others and how it helped them so much - we are sure that the sessions format will be repeated at a meeting in the future. Afterwards the raffle and 100 Club were drawn.

ROSIE'S PROJECT

'Rosie's Project' has been at the forefront of branch fundraising for a long time and has faced many setbacks and dead ends - but now we have a lot of light at the end of the tunnel and all thanks to the University of Cumbria, Lancaster. Rosie has attended meetings at the Uni and is now waiting for a quote for the production of two, possibly three ten minute films covering a fictional person's journey with GBS that will be part of the university's nurse training platform 'Stilwell'. We are pleased to say that the project and the films have been approved by the charity's Trustees and once the finances are agreed and the contracts signed, filming will commence. Further updates will follow.



Tom Dixon's GBS Journey

We first took my dad to A&E on Friday 3rd July 2015; he had pins and needles in his hands and numbness in his toes. We saw Dr Sultan, a stroke consultant, who said it wasn't a stroke as it had affected both sides of his body. With no explanation for what it WAS (rather than just knowing what it WASN'T) we were sent home. During the week that followed his condition worsened, two visits back to hospital for a brain scan and neck scan showed nothing and he was sent home both times, barely able to

walk. I Googled his symptoms and came to the conclusion it was Guillain-Barré syndrome, on Sat 11th July we took him back to A&E and told them what we thought it was, we were told it was very rare and unlikely to be that - and got sent home AGAIN. The next morning, unable to stand, we took him back again and this time he was admitted. A series of scans and x-rays still gave no indication as to what was wrong but finally a lumbar puncture on Fri 17th (two weeks from onset) confirmed it was AMAN (Acute Motor Axonal Neuropathy) strain of Guillain-Barré syndrome. He was started on IVIG straight away. The GBS continued to slowly paralyse my dad over the next 10 days and he moved to ICU on 27th July unable to breathe, we had no idea at this point how long he would be in there.

By the time August was out he'd had a round of plasmapheresis (to no effect), pneumonia and a blood transfusion. His kidneys were no longer working properly and we were told he was likely to be in ICU for 3-6 months.

September started with another round of plasmapheresis, another infection and delirium. He was still totally paralysed and showing no signs of recovery. I contacted GAIN on 7th Sept and was put in touch with Norman Druce who had had GBS in his 60s and gone on to make a good recovery, he'd spent 59 days in ICU, I hoped my dad wouldn't be in there that long. How little did I know! By mid-September he had pneumonia again and was drowsy and hard to lip read on most of my visits. I spent longer in the waiting room than I did at his bedside as it sometimes took over an hour to get allowed on to the ward and he could only cope with about 40 mins of visiting. He had his 68th Birthday in ICU (21st Sept) still fighting off the pneumonia unable to move or breathe. The month ended worse than it had started. On Fri 25th, I went to visit and he seemed more drowsy and delirious than I had seen him before, I asked the nurse if he was going to die, she told me she would get a doctor to come and speak to me. I waited hours. The doctor told me that my dad wouldn't ever recover, he'd be paralysed and on a ventilator for the rest of his life until a heart attack or infection eventually killed him. He said there would be a multi-disciplinary team (MDT) meeting the next week to discuss switching off the ventilator as the kindest thing to do. That weekend the family came to visit to say their goodbyes. The MDT meeting came and we were told the same thing as the doctor had told me previously, dad would never recover and always be paralysed. They were going to do another nerve test to see if the axonal part was still being damaged and if so go ahead with switching the ventilator off, if it was the myelin sheath then they wanted to try steroids to try and get him to breathe for himself although he would always be paralysed.

October and the results of the nerve conduction tests - The axonal parts were severely damaged and the myelin sheath inflamed. The consultant wanted to go ahead with the high dose steroids for 4 weeks to see if it would make any difference. Meanwhile my dad actually seemed to be worsening, he could no longer close his eyes and had to have them taped shut at night, when we visited he was extremely tired and sometimes completely unresponsive. By Sunday 18th Oct he was having another chest x-ray as he had the symptoms of yet another infection, he also had little clusters of blisters on his arm that were being swabbed and tested. We found out the next day that he had shingles and he was moved into isolation, still within ICU. The shingles seemed to mark a turning point, they were able to put him on a 'spontaneous' setting on the ventilator that allowed him to do the breathing for himself for short bursts, he could sit in a chair for 30 mins at a time and by the end of the month he could move his head from side to side. There was another MDT meeting at the end of the month, the consultant explained that the steroids had weakened his immune system and made him more prone to infection - hence the shingles. They were, however, helping with his breathing so they wanted to continue them for the foreseeable future. He was to have 1g a week as a single dose injected straight into a vein.

November and dad was spending more and more time on the spontaneous (SPONT) setting on the ventilator. It was Friday 13th that dad moved his fingers for the first time. Things were looking up at last!! His progress came on almost daily, he could move both hands then both arms and more importantly they were able to start weaning him off the ventilator. By the end of the month he could move his feet side to side and cope for longer sitting in a chair.

December and the ventilator weaning was going well, by Christmas day he was only on the ventilator at night through a face mask, the tracheotomy tube had been removed and he could move all four limbs and speak!

On Weds 6th January dad left ICU after 163 days and went on to the high dependency unit, 10 days later he moved to the rehab unit to begin his recovery.

The months that followed were filled with physio and OT support and goal setting meetings. His feeding port in his stomach wasn't removed until the end of Feb even though he was eating by then and his night ventilator was taken away in April. By the start of May he could stand for a few minutes (with support) and by the end of May he was walking with a frame - all this from the man who was going to be paralysed and on a ventilator for the

rest of his life! At the start of August, after over a year in hospital, he walked unaided and on 16th he came home.

My dad is now 71 and lives independently in his own home, he can walk for a mile without support and only occasionally uses a stick. He has a strange sensation still in his fingers and part of his right foot but other than that he considers himself to be very lucky. We faced some very harsh times in ICU and those 163 days were mostly filled with the words 'no change' or 'another infection' with the outlook bleak to say the least. If I had read this account of another man's recovery at that time I would still have thought 'well good for you but we won't be seeing any sort of recovery' yet here we are. It's easy to believe everything they tell you in hospital, especially when months go by with no improvement but there is always hope, sometimes people beat all the odds!
Written by Lynn Howarth, Tom's daughter.

Before Tom was taken ill he was and still is a very talented watercolour artist, each of us who attended the September meeting were all astounded and thrilled to see a recent study of an elephant...it was truly superb! This painting was done to see if his hands and fine motor skills had been affected by GBS, we are so pleased to say that they hadn't - sadly, because of the pastel colours it has proved impossible to replicate the image in the newsletter.



We would like to remind everyone that our **Christmas Party, Tortoise Drive and Jacob's Join** is at 2pm on Saturday 8th December at Bilsborrow Village Hall - please do come along....an afternoon of fun and laughter is guaranteed.

Sybil and all the committee send sincere and heartfelt thanks to all of you for your continued support, and we look forward to meeting you all again at the meetings next year.
Wishing everyone a Merry Christmas and a peaceful & Happy New Year!



MEETING DATES FOR YOUR DIARY 2019



CONTACT DETAILS FOR THE LANCASHIRE & CUMBRIA BRANCH:

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