

Winter issue 2014/15

In September we held another successful meeting which was very well attended. Sybil welcomed everyone including Freda who came for the first time. We saw the welcome return of our guest speaker Steve Williams whom we all know from his previous visit to the branch. Steve's talk this time was 'First World War Battlefields - then and now', he presented it with much thought, lightening a dark subject admirably and without lessening the true horrors of WW1, he even had us smiling on occasions. Steve has made many visits to the battlefields in France, Belgium, Holland and Turkey, organising and leading numerous coach trips to the Somme, Ypres and Normandy, he is also the co-founder and secretary for the Chorley Pals Memorial and Chairman of 'Chorley in the Great war', Steve also writes books and articles on the subject as well as appearing regularly on BBC Radio Lancashire. Sybil thanked him for a most interesting and informed talk.



Tim held the usual raffle with some great prizes, he was kept very busy on his well stocked stall, there was all the new regalia and items for sale, Christmas cards, pens, t shirts, wrist bands, shopping bags etc, etc., all printed with the new logo. Refreshments followed with members joining in with questions and answers and chatting amongst themselves, including lots of laughter.

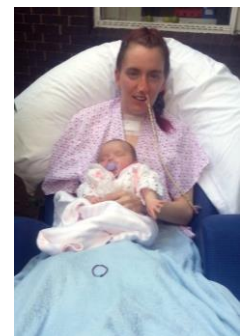


XXXXXXXXXX

Our branch consists of members who have had or are still suffering from GBS, CIDP and other neuropathies and quite a few of us suffer residual symptoms. We can have as many as up to thirty attendees at the meetings covering all ages, one particular member we are proud of is a young lady named Kayla, she comes with her partner, William. We have watched Kayla progress from a wheelchair to frame, and now with a stick, Kayla is such an inspiration to others and we are so pleased she is sharing her experience.

Kayla Bufton- CIDP

My journey began in April 2013. I was a stay at home mummy with my two beautiful boys, and William my partner. I was healthy at thirty five weeks pregnant, excitedly looking forward to the birth of our daughter who we had already named Kelsey-Mae Patricia. I started with unbearable back pain, after a while as it wasn't getting any easier I went to the hospital thinking I had gone into early labour, they admitted me for an overnight stay as my blood pressure was low, by morning I was sent home as the baby didn't seem ready to be born. As the day progressed my tongue felt all tingly like I had burnt it on a hot cup of tea, then my hands and feet felt tingly and I became totally exhausted, I tried to get some sleep and rest but the back pain was so bad I had to visit my GP, it was all put down to the pregnancy and I was advised to rest, which was nearly impossible. Over the next twenty four hours the pain came and went so I did manage to fall asleep, but on awaking I realized something was seriously wrong as my face had dropped on the right side, I shouted for my mum who had stayed to help William with the children. We rang 111 and an ambulance arrived and took me to A & E, then I was transferred to the medical assessment ward where I was now diagnosed with Bells Palsy, they gave me steroids to take and I was discharged. I went home but I couldn't stop being sick and my balance was



affected, I managed to sleep for a while but over the next twenty four hours I got worse, I woke up to find both sides of my face had dropped and I had lost the use of my right leg and kept dropping to the floor which was very worrying being so heavily pregnant, I knew there was something very seriously wrong but no-one was listening to me.

I managed to get an appointment with an out of hours GP who suspected I was having a stroke, I saw a neurologist who immediately sent for an ambulance to take me to The Royal Preston Hospital where I was seen by another consultant who diagnosed Guillain Barré Syndrome, I was then given an explanation of what can and might happen. The horror of the situation hit me, 'What about my baby girl about to be born, is it going to happen to my baby, is she going to be ok'. I was admitted and things went from bad to worse, I was put on oxygen and needed a feed tube as by now I couldn't swallow. On the second day 9th May 2013 at 5.15am I went into labour, it was a long and stressful labour and I was now getting weaker by the hour, but my little baby girl arrived safe and healthy weighing 4lb 15oz, she was perfect but had to be taken to ICU to keep her temperature at the correct level, at this point I was transferred to the neuro ward. I was extremely exhausted and sore after a natural birth but the feeling of emptiness overwhelmed me as I was separated from my new baby. Two days later Kelsey-Mae went home to be with her brothers, nana and auntie, while I stayed in hospital. The following day 11th May my breathing was affected and I was rushed to ICU to be intubated and later remembering waking up with my partner William at my side holding my hand, I tried to move but couldn't, I was paralyzed from my eyes to my toes, I couldn't even shut my eyes, I was trapped in my own body, there were tubes everywhere, but the first thing I could think of was my children, I need to go home to look after them. How could my life go from perfect to the deepest hell within two weeks? What did the future hold, would I ever be able to walk again, no-one could tell me.



Over the next few weeks I was pretty much in my own world, hallucinations became the norm, some funny ones and others were horrific, I could see family members sitting round the bed and staring at me, I would try to talk but it was mostly rubbish, I could see in their eyes things weren't good. I didn't know the date or how long I had been there as the days just rolled into one, but I did know I hadn't seen my children for weeks and I was pining for them, I worried that my new baby Kelsey-Mae wasn't going to know who I am. It was on my 24th birthday that I was taken off the oxygen and put into a coma. In due course I started to come round from the coma and mum would read my get well cards to me, I now started to get very slight movement after a course of IVIG, I learnt how to communicate with family members using my eyes and an alphabet sheet, but I would get very frustrated if they couldn't understand what I was trying to say.

Another few weeks later and I started to improve, I felt movement coming back in my hands and fingers; I started to use the speaking valve and trained my breathing ready for the tracheotomy to be removed. I remember the first day I used a hoist; the pain was unbearable but couldn't tell the staff, my legs felt like they were being pulled off my body. When I sat in the chair it felt like thousands of pins stabbing my entire body, and at this stage I couldn't hold my head up. Eventually I was moved to the ward still with the tracheotomy in, and I could sit in the chair more comfortably, most importantly my children could visit me every day. I was now determined to beat this illness and go home to where I belonged with William and my children. I started to use a standing hoist with the physiotherapist and although the pain was still severe it was worth it as it was nearing the time to be allowed home for short periods.



August arrived and I was allowed home for the first time, it is a day I will never forget, I realized how much I had missed being away from the children so long, the boys had grown and Kelsey-Mae had started to smile, I felt it so unfair. By the end of August it was approved that I could go home until rehab was organised, I was still bed bound or chair bound but I was home with the children, William and my family. It was October 2013 when I was transferred to rehabilitation to begin the hardest phase of my recovery, I did start to improve more quickly from this point, and in February after four months in rehab I was out of my wheelchair and walking with a frame. March came and I had a setback with the symptoms returning, so had to return to The Royal Preston Neurological Hospital for a course of ivig, eventually I was diagnosed with CIDP. April 2014 and going home at last walking with a stick, home to my family.

Where am I at now? I have fortnightly treatments of IVIG and steroids. Sometimes I still have neuro pain in my feet and I ache, fatigue is persistent and some days I really struggle, but my life is going good at the moment. I am

grateful for the support I had and still have, William who has stood by my side all the way, I couldn't have got through it without my family. I love my princess Kelsey-Mae who is mummy's little girl, my boys Mckauly-Dean and Kayden, I try my best now to do activities with my children and be the best mummy I can be, we have lots of fun. I am grateful for the life I have and the people in it. If it wasn't for Guillain Barré' Syndrome I wouldn't have met some of the most amazing people, the staff at The Royal Preston Hospital, staff at Rakehead Rehabilitation unit, and the lovely people of the Lancashire and Cumbria support Group who have been a great support.

XXXXXXXXXX

The Lancashire and Cumbria Branch was created over twenty years ago to meet the needs of people in the area who suffer from GBS/CIDP and associated neuropathies. We have open meetings at the Village Hall in Bilsborrow which is situated on the A6 midway between Preston and Garstang; these are held four times a year on a Saturday at 2 pm. We generally have a guest speaker followed by a question and answer time slot, this gives the opportunity for members to exchange experiences and socialise over refreshments. One of the aims of the branch is to offer encouragement and support during recovery as required via our local area contacts, also we are in the early stages of bringing to fruition 'Rosie's Project'. We have ten dedicated members on the committee who work hard to make our social meetings interesting and supportive, Gerald joined the committee this year and he has become such a valuable colleague. We would like to welcome Glenis on to the committee, she will be joining us for the first meeting in December and she has also kindly accepted our invitation to take over the 100 Club. Glenis and her partner Andrew have been members for a few years now and we are so grateful to them both for all their help at the meetings.



XXXXXXXXXX

YOUR RIGHT TO SEE YOUR MEDICAL RECORDS- BY GERALD WILSON

When I retired in 2011 with over forty years service, my number of days absence due to sickness had hardly got into double figures. Up to that time my experience of the NHS had therefore been rather limited, however, since my diagnosis in 2013 with PDN, a variant of CIDP, it all changed. With numerous tests and consultants not to mention a week's stay in hospital for IVIG treatment I began learning fast. As far as the medical care is concerned I must say this has been of the highest order, both professional and compassionate. Nevertheless, problems arise with the administration system that is an essential part of any large organisation. Time and again it seems that test results get lost and communication between one part of the organisation and another breaks down, yet, as a patient there are a few things one can do to help oneself, and I would like to pass on some tips.



Your GP is the hub of your contact with the NHS; it may not seem like it when it is the hospital you visit for appointments, in spite of this each consultation or stay in hospital will normally lead to a letter being sent to your GP. Ask the consultant to send a copy of the letter to yourself, it will remind you of what was said and also give you the opportunity to 'Google' those complicated medical terms or names of drugs that went in one ear and out the other, it helps with an understanding of your health. If, for any reason you don't receive a copy of the letter ask the receptionist at your GP surgery, I did this and copies of several letters were

handed over without question. This approach really paid off for me in a recent consultation when the neurologist said that he didn't seem to be able to access my notes on the computer system. I felt quite smug in being able to offer my copies back to him to jog his memory.

Another recent experience was that I was referred for a second time to a haematologist but not to the same one as the first time or even the same hospital. Now I already knew that sharing of notes between two hospitals just doesn't happen, so prior to seeing the second haematologist I took steps to get the notes of the consultations with the first one. Well, it might avoid the need for more needles to be stuck into me and might even save the NHS some money! On the contrary, a straight request to the consultant's secretary was refused and instead I was referred to 'Data Access' at the hospital concerned. This is a system, whereby any request for medical notes must be fulfilled within forty days. As the notes were quite recent and I was able to be quite specific as to what I wanted, the requested information came within a week or so. The second haematologist was very pleased to receive them and I believe it saved the need for a second CT scan.

Modern medicine is dependent on a multiplicity of tests; unfortunately the admin system has not been developed to cope with this. Most of the time the test results get lost even between two specialists in the same department. Whenever I have or am going to have a test I always ask how long the results will take and how I will get to know them. If I haven't heard in that time then a call to the consultant's secretary usually elicits the response that they haven't been received as yet. A second call to the test department then usually generates the response that they were sent a week ago, but they will now resend them. I have lost count of how many times I have heard this story!

Yes, I have found that in this great machine that is our NHS it pays to look after your own interests, in short:

- Always get a copy of letters to your GP
- If necessary don't be afraid to use 'Data Access' as a means of getting hold of hospital notes
- Always chase up test results

XXXXXXXXXX



WISHING YOU ALL A VERY MERRY CHRISTMAS AND A HEALTHY AND HAPPY NEW YEAR



2015 MEETINGS – 2.00PM – BILSBORROW VILLAGE HALL, BILSBORROW	
MARCH 14 TH	AGM
JUNE 6 TH	PLANT STALL
SEPTEMBER 26 TH	TO BE ARRANGED
DECEMBER 5 TH	CHRISTMAS PARTY, JACOBS JOIN
SPEAKERS TO BE ARRANGED	

The support group is a registered charity that offers support and information for those who are affected by GBS, CIDP and associated inflammatory neuropathies.

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

Gain (formerly GBS Support Group), Woodholme House, Heckington Business Park, Station Rd, Heckington, Sleaford, Lincolnshire. NG34 9JH

Tel: 01529 469910 Email: office@gaincharity.org.uk Helpline: 0800 374 803