



Guillain-Barré Syndrome Support Group
Lancashire and Cumbria Branch
Bilsborrow Village Hall
Bilsborrow
Preston

2013/14 Winter issue



All too soon it's time to wish everyone a Happy Christmas and a very healthy New Year from all of us on the Lancashire and Cumbria Support Group committee. We've had a good year with interesting meetings and wonderful support for the start of fundraising towards '**Rosie's Project**' for children, including a successful coffee morning, a wheelchair walk, gardening work, a cycle tour of Wessex, collecting printer cartridges, plant stalls, raffles, shoe sales, donations and many more, of which we would like to say a big thank you. There are further plans for fund raising ideas in the near future and with your help we will raise the amount required. We were delighted to welcome six new members who came to our September meeting, Kayla and William, Kayla is hoping to be out of her wheelchair soon but meanwhile, with Williams help they intend to do a wheelchair walk from Blackburn to Preston to boost our funds for the project. Tina and Bob, and Gerald and Fiona came for the first time. A very warm welcome to all of you.

We hope to see all of you at our **Christmas Party on Saturday 7th December**, in addition to our usual Tortoise Drive and 'Jacob's Join' we have a very special surprise guest. Those of you who accompanied us on the Oswaldtwistle Mills trip may guess, it is a little naughty and full of laughter, come with a broad mind, his books and cd's will be available to buy for Christmas presents. Thanks to Ann and Colin with Joan's input for arranging the trip out in September, and Mike H for coercing our guest into entertaining us at the Christmas meeting. A 'Jacob's Join', in case you don't know what it is, and I didn't until I moved further north from Manchester, it means everyone brings something for the buffet, either savoury, sweet or an accompaniment.

It is time to renew your 100 club membership at the end of the year, a form is enclosed with this newsletter, it is £15 per number, and the 1st prize of £15, 2nd prize of £10 and 3rd prize of £5 are drawn for every month. Please fill in the form and send it back to George.

I think the Lancashire and Cumbria support group branch is one of the most active, but we couldn't do it without the hard working committee and our stalwart members. Thank you and god bless you.
Sybil (chair)

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At the June meeting we held our usual plant stall followed by guest speaker Professor Jim Richards who gave an interesting talk on gait.

Professor Jim Richards
Department of Biometrics
Allied Health research unit
(UCLan) University of Central Lancashire

This presentation was about research done in the Allied Health Research Laboratory Unit at UCLan. Some would see this as a sports injury unit, but the implications of the research go much further. As well as gait analysis, it covers studies related to a broader range of physical problems which lead to restriction of bodily movement. This not only includes physiotherapy but also involves osteopathy, podiatry, speech and language therapy, sports therapy and many other allied specialisms.

Jim's qualifications and experience have been initially in Mechanical Engineering leading to Bioengineering and then a PhD in Biomechanics. This has taken him to a variety of academic institutions. In 2004 with this broad range of experience he was appointed to establish the research unit at UCLan, Preston. The laboratory comprises a range of over



30 television cameras and assorted infra red sensors linked to computers. These are able to produce three dimensional pictures of patient’s movements and gait. If there are abnormalities they can be detected by making comparisons with examples of a ‘normal’ person’s movement. From this, the reasons can be analysed. These may be due to muscle weakness or restrictions due to joint injury or deformity and a sound basis for compensatory treatment can be prescribed.



Jim opened his presentation by saying that:

‘The department does not believe that an individual’s recovery can plateau with no further treatment being possible or successful’

From this it would appear that in the past, physiotherapy has taken the form of a series of blanket exercises recommended as a means of compensating for injury. However, this approach did not necessarily cater fully for an individual patient’s condition and eventually a plateauing effect could be reached. At this point the physiotherapist would confess that nothing more could be done to alleviate the problem and the individual would then be ‘signed off’ and left to their own devices. Many GBS sufferers will have experienced this.



On the basis of his work Jim explained that modern research has revealed 150 measurable features which are involved in walking. Through the use of filming in the laboratory, movement can be analysed and measured and used to assist in the development of regimes of physiotherapy planned to satisfy the *specific needs* of each individual. Analysis of impairments to other parts of the body may be similarly quantified. The difference between normal and abnormal gait and stance was explained and illustrated through the use of automated skeletons. These provided graphic comparisons between restricted and normal movement and went some way to provide reasons and explanations for deformities.



Developments within the department relate to the formation of partnerships with industry concerned with the design, development and testing of biomedical aids. This is in line with

Jim’s engineering background and has proved to be a successful avenue in the acquisition of funding for further research.

In terms of the experience of those of us having had GBS and those continuing to suffer from the after effects the presentation was a most enlightening afternoon. In relation to those suffering CIDP, funding has been obtained for an extended study alongside The Royal Preston Hospital. We await the results with interest.

For information on Professor Jim Richards and his department go to Google and search the extensive entries including the illuminating one on You Tube.

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Rosie’s Project

As some of you will know, 17 years ago my daughter Jennifer, then aged 5 was taken ill with Guillain-Barré Syndrome. In a nut shell, she spent three months in hospital, six weeks at the Royal Manchester Children’s Hospital on life support in the Intensive Care Unit and a further six weeks in our local hospital. It was a long hard road to recovery and during this time it became more than obvious that there was a lack of knowledge about GBS especially in children. During and after this traumatic event, and after speaking to other parents who had found themselves in the same situation via my role as a **Child/Parent Contact** for the GBSSG (Guillain-Barré Syndrome Support Group), it became apparent that the medical profession still had a lot to learn in the care of children with GBS and associated neuropathies. With this in mind, my hope has always been to help children and their families cope with the illness and to alleviate the specific worries associated with paediatric GBS. Not wanting to sit on the fence, I persisted to push forward with an initial idea, fortunately I had the support of the committee members of the Lancashire & Cumbria branch of the GBSSG, and they have never failed with their encouragement, although we did have quite a few dead ends and false starts. But, recent developments now mean we have moved away from the initial format and now find ourselves with a new and far more exciting replacement – details of which will be revealed in due course. However, and this is where we need your help, (there’s always a catch), in order to bring this important project to life we have



to raise funds.....so, if anyone fancies doing something, anything, which will help us to fund this vital project, please get in touch with myself via facebook or head office at Sleaford to register your details.
Rosie.

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On Wednesday 11th September members enjoyed a trip to Oswaldtwistle Mills, Oswaldtwistle, Lancashire, known locally as 'The Bubble Factory'. 'The mills' was originally a cotton weaving mill but is now an award winning shopping village full of character with many unique retailers and four restaurants. Our group joined other groups in the 'Hungry Tackler' restaurant for a delicious homemade three course luncheon followed by live entertainment with time for shopping in between. The theme of the day was 'Lancashire' and the Phil Knight experience and Steve Morris gave the most hilarious performances that had everyone laughing. The Phil Knight group sang some really funny LANKY folk songs including 'Sarsaparilla' and 'The Rawtenstall Annual Fair'. Steve Morris who writes in humorous verse gave the funniest performance of poems and monologues in Lancashire dialect. A lot of his stories are about northern folk with the added addition of Steve's imagination.

Eh, by gum, thowt it wor a reet good do, un wi all went wom. Si thi in December!!!!

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JOHNATHAN MOORE - SPONSORED TOUR OF WESSEX JUNE 2013

June of this year saw my son-in-law Jonathan take part in the Tour of Wessex as reported in the previous newsletter. Throughout his life Jonathan has been a keen sportsman, a cricketer and footballer and is always up for a challenge. Until recently he took part regularly in triathlon events but now concentrates on cycling and train the local youth football team.



As a result of my experience of GBS and its aftermath, Jonathan saw firsthand the effects it can have on the individual and the arduous road to recovery. He then found out children can suffer the syndrome and the fact that Rosie is particularly involved through her project gave him the excuse to embark on yet another challenge, and so



he obtained sponsorship for a very worthy cause. The Tour of Wessex' is a cycling event which involves 360 miles and 21,000 ft of accent. It takes place over a three day period and is set in the rolling hills of Somerset. Preparation took the form of a fairly intense training scheme over a period of six months, during which time he obtained funding and sponsorship from a variety of family, friends, colleagues, acquaintances and business colleague's contacts. Eventually he was able to raise well over his target of £3,500.00 for 'Rosie's Project'.

The photographs show Jonathan wearing the GBS logo which he had emblazoned on his shirt throughout the tour, and eating the most delicious 'bacon butty' that he dreamed of throughout the final 30 miles en route to the finishing post.

John Haresign

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Guest speakers at our social meeting on Saturday 21st September were James Babington Smith, Chairman of the National GBS Support group, accompanied by Caroline Morrice, Office Executive, at the invitation of the branch committee. The turn-out was excellent and twenty three of us were treated, firstly to splendid buffet lunch, prepared by Ann, Rosie and Joan with supporting sandwiches from the White Bull. After a warm welcome Jamie and Caroline gave members an update of the latest developments within the group with many informative questions and answers where we learned something of the history of the National GBS Group and the constraints placed on it more recently due to tightening of the rules by the Charities Commission. It was this action that led to the change of our name to GAIN (Guillain Barré and Associated Inflammatory Neuropathies) in order to make our broader outreach clearer in the title.



Caroline explained about other requirements expected of the national group which included supporting local branches, such as ours. The Charities Commission also expect H.O. to encourage the creation of new branches. As the oldest branch in the country, we offered whatever advice and support we could give to anyone wishing to do this.



CAROLINE MORRICE, OFFICE EXECUTIVE (LEFT), SYBIL LOXAM, NW BRANCH CHAIR (CENTRE), JAMES BABINGTON SMITH, CHAIRMAN OF THE NATIONAL GROUP (RIGHT)



Our members – there were six new ones on the day – had numerous questions, both concerning their own experiences and also about fundraising for our Children’s Neurological Project (Rosie’s Project) of which is mentioned earlier. Jamie explained that it was quite acceptable for funds we raise to be ear-marked for that specific reason. He also confirmed that Head Office will match whatever funds we can raise.

Everyone who commented on the meeting said how much they had appreciated the relaxed atmosphere, the opportunity to meet Jamie and Caroline and learn about the Support Group. Finally Sybil thanked them both for donating their free time to attend our branch social and meet and chat to members



Caroline and Jamie (front right) with the North West branch committee members

2014 Meetings - 2.00pm - Bilborrow Village Hall, Bilborrow

- MARCH 15th AGM, SPEAKER TO BE ARRANGED
- JUNE 7th PLANT STALL, SPEAKER TO BE ARRANGED
- SEPTEMBER 20th SPEAKER TO BE ARRANGED
- DECEMBER 6th CHRISTMAS PARTY, JACOBS JOIN, TORTOISE DRIVE

EVERYONE WELCOME



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

The GBS support group is a registered charity that support those with GBS, CIDP and related conditions.

For further information or support contact;

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