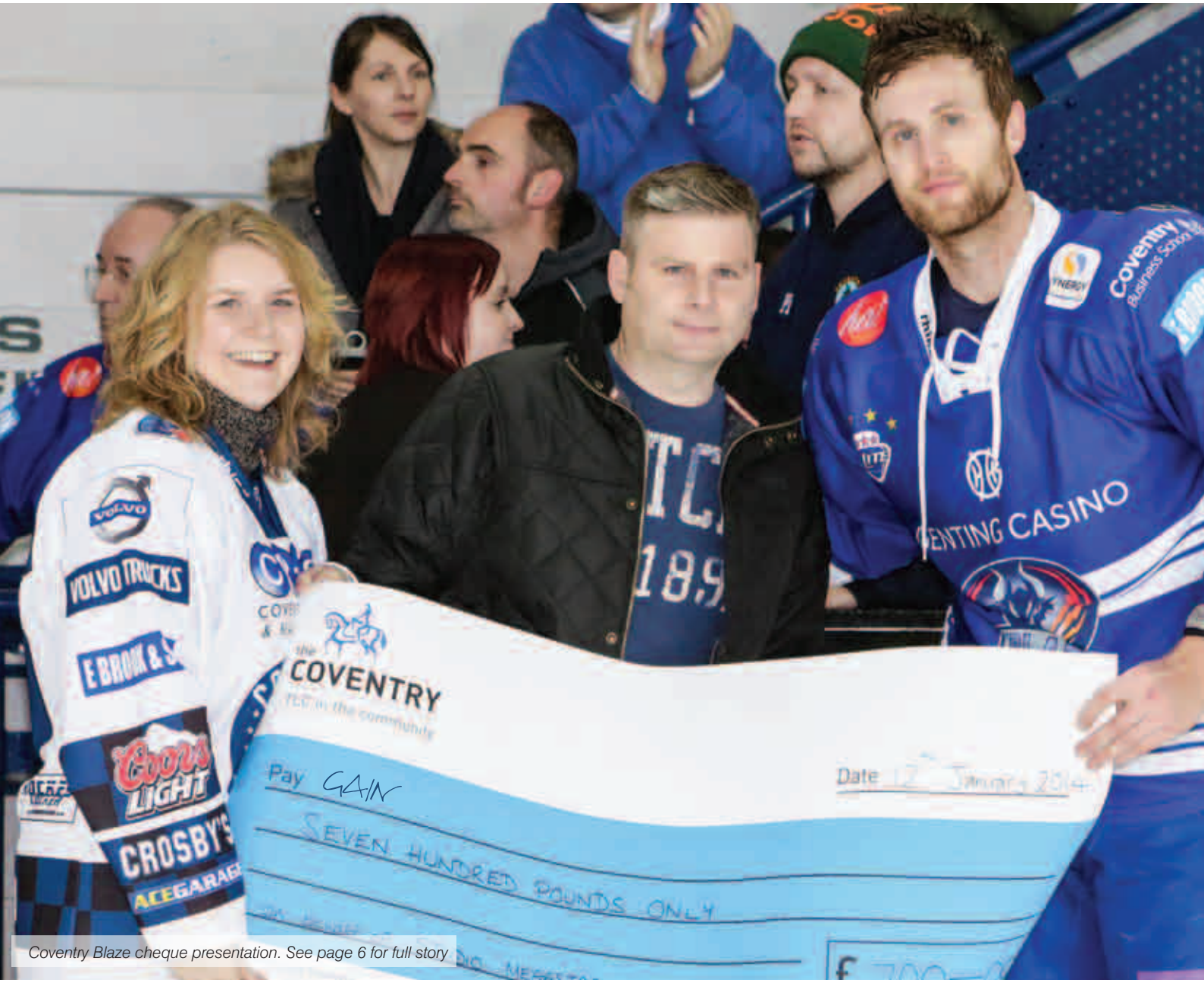
gain4all

SPRING 2014

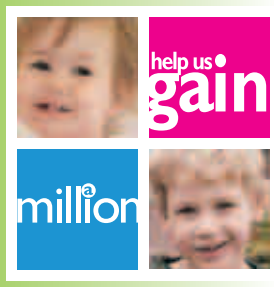
Issue 1

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies



Coventry Blaze cheque presentation. See page 6 for full story

www.gaincharity.org.uk



gain a million

fundraising appeal

Leading up to the centenary of when Drs Guillain & Barré identified GBS in 1916, the charity is re-launching a **gain** a million fundraising appeal with an initial target of at least £1 million.

Around 1,200 people are affected by GBS annually in the UK with a further 500 being diagnosed with CIDP. About 80% of those with GBS will make a good recovery, but unfortunately 1 in 10 people will die as a result of the condition and the other 10% may experience long term residual effects ranging from limited mobility or dexterity, to life-long dependency on a wheelchair.

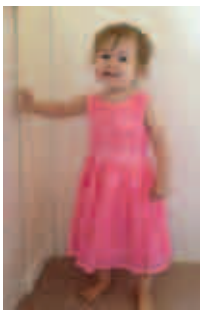
The charity exists to provide support and information to patients and their families, to raise awareness of these conditions and to attract funds for research. Sadly, as a relatively rare condition, GBS/CIDP attracts little interest from the major research funders and pharmaceutical companies, thus our contribution to funding research is of major importance.

Your help in supporting our work and ultimately helping families such as Amy's and Ben's (below) at difficult times is greatly appreciated. To reach our target by the 100th anniversary would make a big difference to each and every person affected by the conditions.

Ben Ward was 22 months old when he was diagnosed with GBS in 2009 and still has mobility problems as a result of GBS. Because of damage to the nerves that control his calf and foot muscles, as he has grown, the tightness of his muscles has been deforming the position of his feet. Despite great support from his physiotherapy and orthotics team, Ben has had operations on both feet to help improve his foot position and mobility. Last year, Ben with his family completed the Capital Ring, a 78 mile walk around London and raised in excess of £5000 towards our appeal.

> "the best Christmas present ever

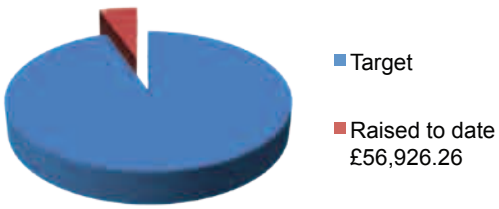
Amy Parr was born via an emergency caesarean in September 2011; she didn't breathe for eight and a half minutes and her heart rate was low. She was taken in a travel incubator straight to the high dependency unit in the special care baby unit where she was assessed. Amy was very floppy, couldn't move a muscle (apart from her head), had a weak cry and a weak swallow. Following numerous tests. Amy was given a working diagnosis of CIDP; her parents were told she would probably never walk and to catch a cold could prove fatal. Thankfully, Amy has made a remarkable recovery, taking her first step on 25th December 2012: "the best Christmas present ever" said her parents, "this was the toughest time we have ever had especially as first time parents – it was like an emotional rollercoaster which we wouldn't wish on our worst enemy."



If anyone would like more information about our appeal or has a fundraising idea and would like our help, please contact: fundraising@gaincharity.org.uk

To help reach our initial target of at least £1 million you can now donate by phone – text:GAIN16 £(amount) to 70070

gain a million February 2014



about
Guillain-Barré syndrome

Guillain-Barré syndrome (GBS) is an inflammatory disorder in which the body's immune system attacks the peripheral nerves.

Severe weakness and numbness in the legs and arms characterise GBS. Loss of feeling and movement (paralysis) may occur in the legs, arms, upper body and face. Severe cases may result in total paralysis and breathing difficulties, requiring long-term rehabilitation to regain normal independence, with as many as 15% experiencing lasting physical impairment.

In some cases, GBS can be fatal. Because the cause of GBS is unknown, there is no way to prevent the disease from occurring.

Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) is a disorder related to GBS that follows a much longer course. Though rarely fatal, many patients seek an effective treatment that often proves elusive.

gain is a registered charity that supports those affected by GBS, CIDP and other related conditions in the UK and Ireland. Please contact us for further information or support.

about gain

The charity has three main aims:

The provision of information, non-medical advice and other assistance;

The promotion of research into the causes, prevention and treatment of Guillain-Barré syndrome and associated inflammatory neuropathies; and

Advancing the awareness of the public and of the medical professions concerning Guillain-Barré syndrome and associated inflammatory neuropathies, their causes, prevention and treatment.

How you can help

As long as people continue to be taken ill by GBS and CIDP, the Charity's work will never be complete. We can only continue to provide our service with the continuing help of our generous supporters. There are several ways in which you can help us and make that extra difference.

- Fundraising
- Make a financial donation
- Become a member
- Volunteer

CONTENTS

gain

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Office Enquiries: 9.00am – 3.00pm

Registered Charity 1154843 & SCO39900

news from the

2014 Conference

The 2014 Conference will be held in Swansea on 17 May at The De Vere Village. Guests will be welcomed from Friday afternoon, where there will be time to enjoy all the hotel has to offer. Whether a gentle swim or sauna , an invigorating spinning class or just a drink in the lounge there are plenty of options for everyone to make the most of their time away and enjoy the weekend.

This year in addition to the top quality speakers and ever popular Ask the Experts session we will be holding some group discussions. These discussions will offer attendees the option of speaking with people that had a similar condition to them; getting an update on volunteering; or maybe you could consider how to help with fundraising – the choice will be yours.

In the evening there will be a dinner, where we will draw the annual raffle and give you all a chance to watch a film about Ben and James who rowed the ocean for us!

For those who wish to seek an alternative hotel, there are two options within walking distance of the De Vere – Premier Inn and Ibis.

Have you been to Swansea or stayed on the Gower Peninsula? No – well you are in for a treat! The Gower Peninsula is both beautiful and unspoilt, and there are many historic features located over an area that measures just sixteen miles by seven miles wide. Notably, Gower was one of the first places designated 'An Area of Outstanding Natural Beauty' under the Act of 1949.

Check the website www.enjoygower.com which aims to highlight and promote the main features and attractions of Gower and the surrounding area, whilst also giving guidance to visitors, helping them to maximise their enjoyment of South and West Wales.

If you wish to add a few days in the area, this can be arranged. Book online through our website or use the form at the end of this magazine.

RAFFLE and TOMBOLA

If you are able to sell raffle tickets for the Annual Prize Draw, please make sure that ticket stubs are returned to head office by 9 May 2014. Tickets are currently being distributed and we have plenty more should you need them – just ask! Due to the success of the tombola last year, we will be having one again this year and if anyone can donate a prize or two (new and unused items only please) we would love to hear from you, t: 01529 469912, email: fundraising@gaincharity.org.uk or alternatively, bring them along on the day. Thank you.

office

New Publication

We have a new 'Physiotherapy' booklet which is available from the office or can be downloaded from the website.

2014 Ride London-Surrey 100

Our four riders for the Ride London-Surrey100 are now all signed up for the big event which takes place on 10th August. Full details about the event and how you can support them will be issued in the Summer edition of ***gain4all***.

gain
Guillain-Barré & Associated Inflammatory Neuropathies

The Charity would like to thank Smith Design for creating the new logo and for all their help with the design/layouts for our booklets and promotional material.

www.smithdesigns.co.uk
email: smithdesign@talk21.com

The next issue of the magazine will be published in June 2014 and the deadline for submissions is 30th April 2014.

report of the EGM

I would like to welcome you to our new charity, Guillain-Barré & Associated Inflammatory Neuropathies, to be known by the acronym, **gain**. The final stages of the merger of the old Group and **gain** started on 25th January 2014 when members approved the merger and the new constitution at an extraordinary general meeting which was held at pjcare Peterborough.

gain was formally launched 3 February 2014, but much remains to be done; should you currently subscribe as a member or supporter, you need to let the office know if you do not wish to become a subscriber of the new charity. The office will be very busy for the next few weeks finalising all the new publications, website and financial arrangements.

I hope you will agree that the acronym "**gain**" will give us a positive image and an easy to remember name. You will find that many of our activities will reflect this; our pamphlets will be headed "**gain** information", our Personal Grants will be "**gain** grants", while our magazines will become a quarterly issue entitled "***gain4all***" and the website "www.gaincharity.org.uk". Finally, our fundraising appeal has been relaunched as "**gain** a million".

We are delighted that we are amongst the first charities in England to convert to CIO status. This puts us in the forefront of reform; the downside is that many of the agencies that we deal with are still trying to work out how to interact with us.

The trustees are confident that we have laid the basis for the future success of the Charity. We will not lose sight of our role in providing support to sufferers, their carers and their families. We are developing new approaches to raising awareness. But above all we will in the next few months be introducing a new approach to fundraising which will complement the very successful fundraising activities undertaken by so many of our volunteers.

We look forward to telling you about the way ahead at our conference in May this year, which will be held in Swansea. I hope to see many of you there.

With best wishes,
James Babington Smith

Chairman Guillain-Barré & Associated Inflammatory Neuropathies (**gain**)

gain4all

fundraising

£1245 Christmas Bonus

Christchurch Group provides a range of rehabilitation and complex care services to support people affected by Neurological Conditions including Brain and Spinal Injuries. As a group we wanted to do something different to mark the festive season of 2013 so instead of the usual printed Christmas Card which would have been sent out to hundreds of contacts we decided to get everyone involved in raising funds for charities. An email Christmas greeting was sent to thousands of contacts wishing them all the very best for the festive season and to ask them to vote for which one of the three charities nominated by Christchurch Group they would like to receive money out of a pot of £1500 donated by the company. Just 2 or 3 clicks on a computer was all that was required from our contacts to spread the festive cheer.

> “just 2 or 3 clicks

As you may be aware, the Guillain-Barré syndrome Support Group was one of those charities… and we are delighted to let you know that through the help of all your supporters, a fabulous cheque of £1245 will be winging its way to the GBSSG! Well done to everyone who got involved.

We are delighted to have supported such worthwhile charities in this way and thank everyone who voted for getting involved. With best wishes for 2014 from all the staff at Christchurch Group

Sheena Kidd
Operational Governance Director

We became involved with the GBS Support Group when my husband, Marcus, was diagnosed with the disease in February 2011 aged 64, after a very bad stomach virus. Although he did not have to be ventilated he lost 75% of his muscle strength. He has made a fairly good recovery, largely due to his own dogged perseverance and willpower, but he still gets very tired and walks with a pronounced limp. We feel it is vital to raise awareness of the disease, especially among medical staff, particularly the importance of early diagnosis and physiotherapy.

The Great North Run was the first half marathon that our son, Jo, had attempted, and he was very pleased with his time of 1 hour 45 minutes. He is now inspired to do more and wants to run the Robin Hood half Marathon with his sister next year, so hopefully our sponsorship base will widen considerably!

Every year the W I in Farnsfield, Nottinghamshire, which is where we live, holds an Autumn Market at which each stallholder raises money for a chosen charity, so mine was naturally GBS. I make glassware from recycled window and bottle glass and sell it at fairs and galleries.

Between us Jo and I raised £300, a modest amount, but it will be added to in the future.

Barbara Coulam, Farnsfield, Notts

reports

Millfield Imps Golf Club raised £714.00 for the GBSSG presenting Caroline Morrice with a cheque at their Presentation Night. All members of the Golf Club are aged 18 and under and are responsible for the organisation of all their fundraising activities.

A Garden Party event, in memory of Candice Roberts, was held on 7th September at the home of Geoff and Ingrid Siddall in Warrington. Geoff and Ingrid are pensioners and held the Garden Party (regardless of the forecasted potential downpours) in their garden – this is the second year they have held the event, the first being in 2011.

They opened their home for Candice and GBS, which was very,very humbling – they collected tombola and raffle prizes, organised garden furniture, rainproof gazebos and the food and refreshments. Geoff even made tables and Ingrid used all her beautiful linen to serve the guests High-tea.

Others who helped on the day also worked very hard selling raffle tickets, manning the entrance and tombola stall, baking cakes and preparing sandwiches; one guest even brought her organ and played music in the garden. All the people attending were also very supportive of Geoff and Ingrid and GBS awareness and fundraising.

Wish me a happy Birthday by making a donation

Elisha raised over £200 by requesting donations in lieu of gifts for her birthday.

"This is me and my Grandad, who, twenty one years ago, had GBS and is still going strong. Forever the role model in my life and if my donation can make a difference to anyone I will be extremely happy" said Elisha.

Helen Flanagan completed the Henley Half-ironman triathlon. Helen raised almost £300 and chose this event because "a half marathon just isn't far enough!"

www.harrys-website.co.uk

"I have been picking blackberries from Regent's Park and making blackberry jam! I am going to be selling my jam and donating all profits to gain, a charity that helped me and my family when I was ill"

Harry (aged 3)

A big thank you to our fundraisers – the Charity really appreciates your support and all donations will make a big difference to sufferers of the illnesses and their families

Ice hockey fan favourite back on the ice

Ice hockey is a sport perhaps most would associate with North America and Canada but this fast paced, physical game is also played throughout the UK.

Canadian Mike Egener is a defenceman for the Coventry Blaze who play in the UK Elite Ice Hockey league (EIHL). Mike spent his first season with the Blaze in 2012/13, quickly becoming a fan favourite. At the end of the season, after re-signing for the following season and having been announced as the new club captain much to the delight of fans, Mike and his family returned home to Canada for the summer months for what was supposed to be the start of a relaxed off season. What happened was the complete opposite…

On 20th June 2013, he set off in the early morning to collect his UK visa. By the time he returned home later that afternoon he and his family were being asked by the police to evacuate their home because of the risk of flooding. Within the next two days, Calgary was hit hard with floods as Mike and his family watched on in total disbelief. It was the perfect storm; continuous rainfall mixed with runoff from a record snowfall in the mountains. The result: Mike's home, located close to the Elbow River, which created the most amount of destruction, was left needing extensive repairs and restoration.

A short while later, Mike started to experience some issues with his health. In an interview with the Blaze, Mike explained how it felt,

"It was shocking. Here I am, a healthy athlete, and all of a sudden I was slowly losing my mobility. I was very concerned and scared. Initially, I thought it was something to do with my heart (circulation) or a pinched nerve in my back until they were both ruled out. It progressed to the point where I needed to go to the hospital. At the hospital they were dumbfounded until the Internal Medical Specialist diagnosed me with GBS. From there, I was put in contact with Dr. Blaine Foell, a Neurologist in Huntsville, Ontario who required me to have the necessary tests done such as: blood work, CT scan, spinal tap, nerve conducting tests, IVIG treatment, etc.

"My symptoms progressed from tingliness in my fingers and toes to the point where I had a tough time walking, climbing stairs, or even picking myself up."

Mike was forced to contact the Blaze Head Coach Matt Soderstrom to tell him he couldn't take up his place with the club as captain for the 2013/14 season. Believing he would never play pro ice-hockey again, Mike started his rehabilitation and shortly before the start of the season, the club released a statement announcing the news to fans. The reaction from fans was a mixture of shock, sadness and a surge of goodwill wishes for Mike's swift return to good health. Tweeting at the end of August, Mike posted the following messages to fans,

"I'm absolutely overwhelmed by the thoughtful messages. I sure have been thrown a couple curveballs the past few months, but will prevail. Heartbroken I won't be suiting up for the Blaze this year. Loved battling for them and playing in front of the best fans in the EIHL."

Having learnt the news, Blaze fan Aimie Dawson decided she wanted to do something to show support for Mike,

"Being an ice hockey fan makes you part of 'the ice hockey family', everyone pulls together in times of need to support each other. I wanted to do something to show Mike that fans cared and were supportive of him as he battled his illness. Like any professional sport club, we have Blaze merchandise for fans to buy, so I decided to contact the sponsor

involved, Nick Upton at Synergy Graphics, to see if we could produce a charity t-shirt we could sell to raise money for Mike. As soon as Nick said it was possible I contacted the club to set things in motion. The club contacted Mike, and he nominated GBSSG to receive the money we raised."

In the next few months, with the help of Nick and a second sponsor, Chris Hammond at ha-creative design, the Boom t-shirt was designed and was ready for fans to buy,

"There was a lot to organise and do," says Aimie. "The 'Boom' idea came from the sound which is made when a player checks another player of the opposing team against the boards during a game, something which Mike would regularly do! I contacted Lesley at the GBSSG, and after a quick lesson in ice hockey, explained what we were hoping to do and why. It took a little while but we were finally ready to start selling the t-shirts by the end of November."

Whilst plans were underway to fundraise in Coventry, Mike was continuing to progress with his treatment in Canada, receiving IVIG treatment in Huntsville, Ontario. Mike credits the unbelievable care of Dr. Blaine Foell and his staff for getting him back on the right track,

"For me being strong mentally and taking it day by day allowed me to persevere. I am in no shortage of good people who stood by and supported me and were willing to do whatever in order to allow me to heal."

Making steady progress in his recovery, towards the end of October Mike tweeted,

"9 wks ago I was suddenly hit by GBS. Yesterday my Neuro gave me the ok. Today I won a small battle… biked to the local Starbucks :) Thankful"

Mike's continued recovery meant that on 14th November it was announced that he was able to return to play again with the Coventry Blaze for the remainder of the season;

"I was pumped to say the least when finding out I would be returning to the Blaze especially coming back to a place my family loved so much and a team I enjoyed playing for. It's been a tough road back and I'm really looking forward to the challenge."

News of Mike's return coincided with the charity t-shirts being ready to go on sale. They were launched at Mike's first home game against the Belfast Giants. In the sixth minute – Mike's shirt number – fans from both sides showed their appreciation by applauding,

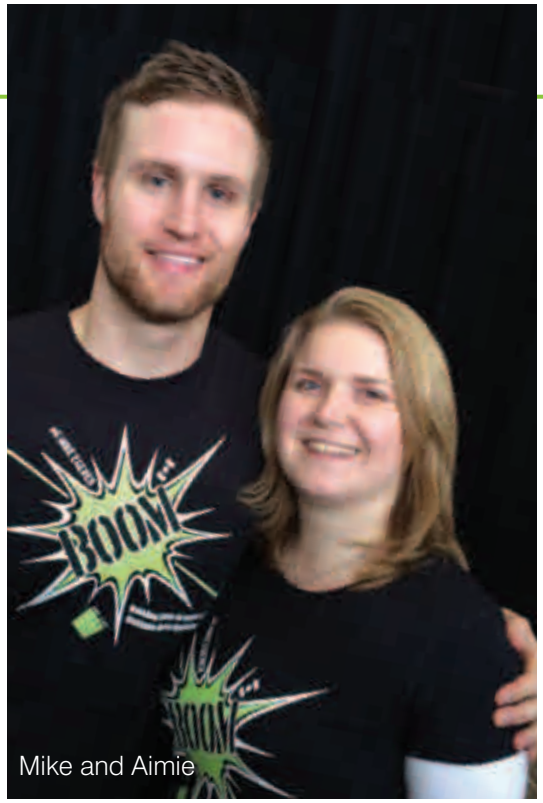
"The sixth-minute salute meant a lot and is something I will always remember. It was a pretty special moment and it was pretty emotional – I am a big softie really! Fans across the Elite League have been so supportive and I appreciate that."

Following the launch of the charity t-shirts, Aimie created a just giving page and a text giving number and set a target of £1000.

"I wasn't sure whether the target would be possible but it was something to aim for."

Then, shortly before Christmas, an impromptu auction on twitter saw £700 raised on one day (front cover pic).

"It was completely unbelievable, what started with someone offering three bottles of wine to the highest bidder, with the money going towards the fundraising for the GBSSG, suddenly snowballed. People were adding to the auction lot as well as bidding. The final prize fund included wine, champagne, spirits, food, various gift experiences,



Mike and Aimie

tickets to a Blaze game, and so much more. We soared through the £1000 target with people making online donations too. The generosity of people was just amazing."

But with over two more months of the season left, Aimie, with the support of other fans, is still working hard planning events to raise more money. A ladies cocktail making experience is planned for March 2014 supported by the Blaze main sponsor Genting Casino, and plans are also underway to host an evening event with a guest speaker before the end of the season.

As well as the events, fans are constantly coming up with ideas to support the fundraising, Aimie said.

"Supporting the team when they play is crucial and the best way to do that is for fans to make plenty of noise during the game. Visiting fans from Canada donated some specially designed cowbells, the sales of which raised £160. Another fan and his family have donated a large jar of change they've saved over the past year and it's our intention to have a 'guess how much is in the jar' competition for fans to win the money. We've reached over £1500 raised so far, it would be awesome if we could raise £2500 before the end of the season. Everyone associated with the Blaze has come together to support the fundraising for GBSSG, it's been hard work at times but it's been worth it. I'm really pleased at how much we've raised and I know Mike is really thankful to everyone who has shown their support."

And the final word from Mike,

"I believe the cliché everything happens for a reason. It has been tough and definitely tested us. It is not how I would have planned it, but it is what it is. I guess that is what makes life interesting; you never know what to expect. My message to the Blaze fans would be, 'You stood beside me while I battled through GBS and I honestly cannot thank you enough. All I can do now is show you my appreciation by battling for you night in and night out.'"

My GBS Story

Jacob Willis

Two years on from the worst period in my life, these dark days when I was wondering what was the point of living whilst locked in an immobile body, I will be running in the Surrey half marathon on March 9th to raise funds for **gain**.

As I've been press-ganged to write up my story, I raided my mum's diary for the time I was ill and have used this to refresh my memory and write my story.

25th December 2011 I woke up on Christmas morning, looking forward to the day ahead like every year, but with one slight change. I started to feel pins and needles in my hands and feet but I took no notice of this and carried on as normal, having completely no idea of to what was to come! The next day, Boxing Day, was when I started to feel the effects; I struggled to lift a jar of custard!

27th December The pins and needles had spread to my calves. I felt weak and found it hard work to even walk. My Mum was worried, so she phoned NHS Direct who sent out an ambulance, only for them to advise us not to go to A&E as it might just be a virus. However the next day (28th December), I was worse as it spread to my knees and I was wobbling all over the place and my legs gave away several times. My mum rang for an ambulance and I was taken straight to A&E where I had a blood test but was told that I only had a virus and was sent home.

29th December My mum and I were still not happy so she took me to my GP where she immediately diagnosed GBS. Blood tests and a lumber puncture confirmed the diagnosis and I was immediately admitted into the Medical High Dependency Unit (MHDU) and started a course of IVIg treatment.

My GBS started to spread, reaching my legs, arms, wrists, shoulders and neck in just 3 days. I found it difficult to swallow, so I had a feeding tube inserted. I still remember the tube being inserted like it was yesterday; as it made me retch. I also had a catheter inserted, which was very uncomfortable and took some getting used to! I continued to get worse over the next few days.

2nd January 2012 The bottom part of my right lung collapsed and I developed breathing difficulties so I was admitted to the Intensive Care Unit (ICU) and put on an oxygen mask. I was receiving continual physiotherapy to exercise my legs, arms and breathing. In the ICU I had tubes put on me what felt like everywhere! On my shoulder, wrists, heart monitor on my chest as can be seen in the photograph above.

The GBS spread to my face, giving me a botox-like look! This caused problems as I am deaf as well as all my family; hence we rely on lip reading and sign language. The fact I wasn't able to move my mouth or hands left me very frustrated, unable to hold a conversation. To make matters worse, I was struggling to have a good night's sleep as I was unable to move to a more comfortable position, stuck to only one place all night long. I started to feel depressed.

Over the next few days I made some very minimal improvements, being able to move my left arm a bit more, but I was in a lot of pain and I had to be given some morphine. I still had to rely on my family to scratch wherever I was itching.

7th January I went outside for the first time since being admitted into the hospital thanks to a specialised wheelchair which was able to support my body. I had never appreciated the fresh air so much before! I couldn't stay out for too long as I found sitting down on the chair far too tiring! Despite going outside for the first time for a while, I felt worse mentally, as I was missing out on my team's football match, the first match they had since I had been admitted to hospital. However my team mates were

thinking of me and sent me a photo of them holding my shirt which helped me a great deal.

The next day, which was about a week after being put on a feeding tube, I had a craving for Coca Cola, like never before!! Whenever someone spoke about food or drink I couldn't listen, it was torture.

9th January I started to feel pain around my ankle, a sign of improvement, and was even able to eat some yoghurt. As I was improving it was decided to move me to a ward for stroke patients as it was thought that this would enable me to receive more attention physiotherapy-wise. I had all the wires, tubes and feeding tube taken out. However the nursing care in this specific ward was terrible.

14th January Unfortunately I soon started to deteriorate, my GBS started to spread yet again and I started to lose the regained mobility in my hands and legs.

Due to my deterioration, a bed was found for me back in the MHDU where the care was much better.

15th January I continued to deteriorate; my swallowing got worse so I had to have a feeding tube inserted again. My mobility was now at its worst; I was paralysed from the neck downwards with a botox like face. It was then decided to give me a second course of IVIg treatment.

18th January My worst day. I was very, very low. I stared to believe my paralysis would become permanent.

20th to 29th January The fact I was now being looked after well meant I started to recover more quickly than before. My family arranged for my friends to visit me, even though I didn't want any visitors. When my first visitor arrived to my surprise, it gave me a massive boost, I realised I needed people around me to support me. I started to cheer up, and had a better attitude toward my recovery. I was able to try to eat and drink once again another real booster.

My mobility was starting to improve again. My left hand was improving faster than my right hand, ironically due to using the TV remote control.

One of my friends, Molly, decided to raise money for the GBS support group by doing a 10K run. This really touched me as she is not sporty at all. I could see I was getting better, this meant my sense of humour returned with a vengeance, and I took joy in winding up my parents and sisters, who visited me every single day.

30th January I was moved to the Neuro-Rehabilitation unit at Woking Community Hospital as they felt I was now out of the 'danger' zone and needed a lot of physiotherapy. I spent the next 3 months at this Unit slowly getting better.

4th February I had my first wheelchair outing with my uncle and his family where I had pizza and a milkshake which I enjoyed immensely. I continued to have sessions of physiotherapy and Occupational Therapy.

19th February The nurses felt I had recovered enough to be able to go out for the whole day with my dad to watch my football team play. It was strange being wheeled around a place where I would normally be walking and running.

February to March Progress was very slow but sure. I was able to finally walk, on a zimmer frame, something I never thought I would be excited about. One of the exercises I had was to try to walk sideways, but every time I took a 'sideways step' my legs kept going forward automatically, us GBS sufferers have to learn almost everything again. There should be 'My First….' Book for GBS sufferers!

5th April I had my 15 minutes of fame, where I was filmed by the BBC, for See Hear, a programme for the deaf, to talk about my progress and recovery. While they were filming, I managed to achieve a major milestone, where I walked unaided for the first time since falling ill with GBS. It was great to have it on tape. Having said this I made the discovery that I could walk unaided the

night before due to a stumble, as I then had to lift my crutches and walk forward faster to regain my balance.

15th April The day before my birthday my group of friends surprised me and turned up with the greatest present, a Manchester United shirt signed by Wayne Rooney. I even got a personal letter from Sir Alex Ferguson along with an autograph from Javier Hernandez.

23rd April After 4 long months, I was finally discharged still on crutches. I started attending the local gym to keep my recovery on track so I could get back to my old self.

20th May I went along to cheer on my friend Molly who was running in the Bristol 10K run to raising money for GBS. Molly wrote about her run in the Summer 2012 – Issue 16 of the "*In the Know*" magazine. I will always appreciate the support she gave me throughout my illness.

July 2012 Being at home really sped up my recovery as I was able to start training with my team mates once again, in time for pre-season and was able to start the football season, although I was weaker and slower than before.

September 2012 I went back to college to resume my studies as I was on an Accountancy course when I was taken ill.

I also went to Dover to cheer my Uncle Matthew Johnston swim the English Channel to raise funds for the GBS Support Group, another thing that I will always appreciate. Matthew wrote about his swim in the Winter 2012 – Issue 18 of the "*In the Know*" magazine.

July 2013 Fast forward to July 2013, 1 year later, I had achieved my AAT qualifications, won the British Deaf Cup (in May) with Fulham Deaf, scoring twice in our 5-0 victory over St Johns in the final. The cherry on top was being selected for the Great Britain Deaf football squad for the first time. We played two matches against France in Paris (in June).

In the summer of July 2013 I went travelling around Europe with Molly which strengthened my legs. Walking every day for hours, with heavy backpacks for miles was something that I thought wouldn't be possible one year back.

I came out the other side of my GBS nightmare stronger with massive help from my parents and two sisters who were there every single day, supporting and loving me. My friends, who travelled from all over the country, visited me regularly. I believe I would not have recovered as quickly as I did without them putting me in a good frame of mind.

Now I am back to my 'old self' if not better! I would like to show my support for the GBS support group, along with Molly and my sister Tamara, by raising money. We will be running in the Surrey Half Marathon this coming March 9th. If you would like to sponsor us go to the link;

http://www.justgiving.com/jmtsurreyhalf

Russian River Cruise

For many years it had been an ambition of mine to visit Russia, particularly St. Petersburg. In February 2010 when I had Guillain Barré syndrome, and was completely paralysed, it looked as if it was something I would never achieve. However, I was able to make a good recovery, and determined in the 2nd life I had been given to make the most of my opportunities. So when my husband retired at the end of 2012, we decided our big holiday would be a river cruise from Moscow to St. Petersburg.

After many months of waiting, and completing the long and laborious process of getting a visa, we eventually flew from Heathrow to Moscow on Saturday 6th July 2013. There was no problem getting through the official controls, and we soon arrived at the Peter the First cruise ship, where we were greeted by music and a lady offering bread and salt, a traditional welcome in Russia. We had deliberately chosen a small boat, one with only 100 passengers, as we did not want to be on a large crowded boat, as GBS has left me feeling uncomfortable with crowds, something many of you will sympathise with.

On Sunday 7th July we set off in the morning for a Moscow city tour. We visited Red Square, which the real meaning of is “Beautiful Square”. This was dominated by St. Basil’s Cathedral, which was very impressive with its brightly coloured onion domes. The next visit on the tour was the Cathedral of Assumption, which although it looks older, they actually started building in 1930, but was not completed until 1990. Russian churches do not have pews like they do in English churches, so people have to stand and some of the church services can last for many hours. We were struck by how religious the people were. In the afternoon we saw the Bolshoi Theatre from the tour bus and then went on to visit the Kremlin. Kremlin means “fortress” and is in effect a walled city, which contains the government buildings and five cathedrals, the most important of which is the Dormition cathedral, which was completed in 1479 and is where the Russian tsars were crowned. Inside the Kremlin it was surprisingly green with lots of trees and flower gardens.

Monday 8th July started with a tour of the metro stations. The stations were a far cry from those in London, and a far more efficient transport system than London with trains running every minute and at 60km an hour (London’s is 40 km per hour). Huge ornate chandeliers and paintings decorated the ceilings of the metro stations. The metro system was built by Stalin to display how wonderful life was under Communism. Very large bronze statues, porcelain figures and pictures depicted various areas of Russian life, beautiful healthy children, farmers with abundant crops, successful sportsman and people enjoying life. There was also an abundance of ceramic tiles and mosaics.

We asked Natasha our guide on the boat and the Moscow city tour guide (both of which were of an age to have lived under Communism), whether they thought it was better as it was then or now. They both thought that each of these times had good things about them, but on the whole they thought that Communist times were better because of the way that people were looked after with better education, job security and provision for the elderly. Coming from the west we would have expected them to say that democracy was far better, and so this came as a surprise to everyone.

In the afternoon we departed for Uglich. We had 1801 km to travel to St. Petersburg (app. 1125 miles) and 18 locks to go through. It gives you an idea of the immense size of Russia when you think this is just one small corner.

We sailed overnight and arrived in Uglich in the early hours of Tuesday 9th July. In Uglich we visited the Church of the Spilt Blood, which was where Dimitri the only

Picture above: St. Basil’s Cathedral, Moscow

living heir of Ivan the Terrible was murdered in 1591. Boris Godunov who seized power and made himself Tsar put about rumours that the death was caused by him having an epileptic fit while playing with a knife. The death of the Tsarevitch Dimitri ended the Rusvik dynasty, and the period known in Russia as the "Time of Troubles" began, with 3 False Dimitris trying to claim the throne. In Uglich we were entertained by a male voice choir. I was then able to try on a Russian costume; the picture shows me in this costume.

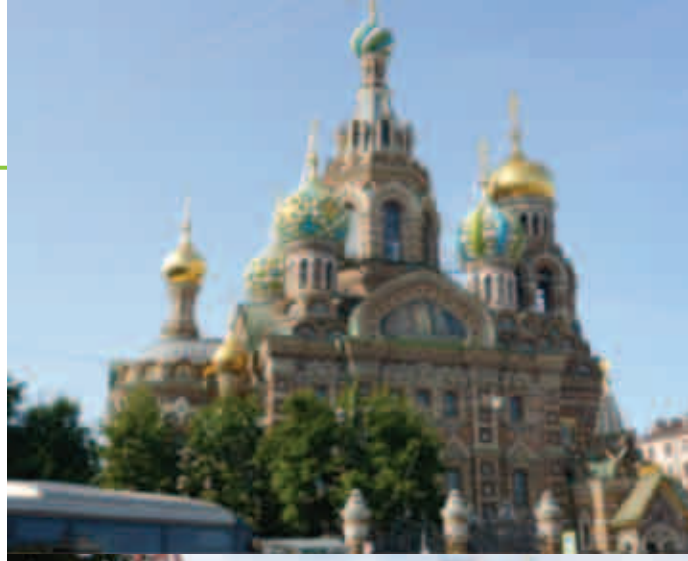
Later that day, as the ship set sail, we had our first Russian language lesson. We learnt some Russian words, sang Russian folk songs and learnt to dance the Kalinka. We also had a talk on safety measures, and had to put our lifebelts on.

We arrived in Yaroslavl on Wednesday 10th July; this town was founded in 1010 by Prince Yaroslavl, which makes it the oldest city on the Volga River. They have a flower display in the park which now reads 1003, the number is changed each year to display the years since the foundation of the city. We then visited a monastery, which had a shop with reasonably priced souvenirs.

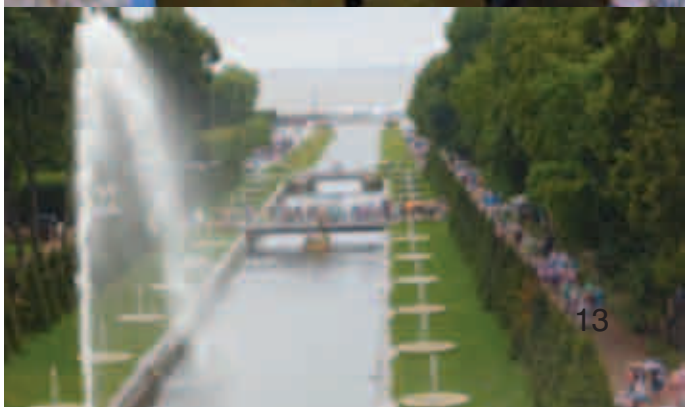
Later that day we had a talk on Russian cuisine. Our journey took us into the Rybinsk man-made sea and saw the Statue of the Mother Volga. When they flooded the area to make this sea, 31 people who chained themselves to their houses because they refused to leave were drowned. The day ended with our nightly concert.

When we woke up on the morning of Thursday 11th July we had docked in Kuzino. This was a very interesting place which remembered its Viking past. They had Viking longboats and a house with displays of Viking armour, helmets and a throne. We then went by coach to Kirillo to the Belozersky Monastery, where 250 monks lived in the 14th Century but there are now only 2.

On Friday 12th July, we journeyed through Lake Onega and the Baltic Canal, passing through 6 locks which Stalin had built by slave labour. During the day we had a visit to the Captains Bridge to see how they operated the ship. We didn't arrive at our destination of Kizhi Island until six in the evening, so this visit was shorter than I would have liked. The Island of Kizhi is home to an outdoor museum of fascinating edifices of northern wooden architecture from various parts of the lake, churches, and farmsteads etc., also the remarkable Transfiguration Cathedral which is original 15th Century. The accepted version of the early beginnings of the island of Kizhi is that it was an ancient







Pictures from top to bottom:
Church of the Spilled Blood, St. Petersburg. Church of the Spilt Blood, Uglich. Russian Costume. Metro Station built by Stalin. Peterhof (Summer Palace)

pagan ritual site for northern tribes. The 1714 Transfiguration Cathedral was erected on Kizhi to commemorate Russia's Victory over Sweden. The Bolshevik government issued a conservation decree protecting the ancient wooden buildings.

On Saturday 13th July we sailed to Mandrogy on the banks of the Svir River. This is a tourist attraction village with craftsman's workshops and a vodka museum. We crossed on a small hand operated ferry to an island which had a zoo with animals found in Russia. During our meeting in the lounge that day the guide told us various stupid questions that people had asked her, these included:-

Do stairs go up or down?

Is this island completely surrounded by water?

Does the crew sleep onboard?

Does the ship generate its own electricity?

What time is the midnight buffet?

Is the water in the toilets salt water or fresh water?

What elevation are we?

What do they do with the ice carvings after they're melted?

What would happen if I flushed the toilet while I was still on it?

If the photos aren't marked with our names or cabins, how do we know which ones are ours?

The evening we had the Captain's Farewell dinner, for although we would be on the boat for another 3 days, the Russians who had been on the boat were leaving the next morning.

Sunday 14th July, we had passed over Lake Lagoda during the night and arrived in St Petersburg at seven in the morning. The lake freezes over in the winter. At nine o'clock we departed for a city tour of the fascinating St Petersburg; it has canals going all across the city, which earned it the title of "Venice of the North". Our first stop was St Isaacs Cathedral, and then we visited the magnificent Church of the Spilled Blood. Our next stop was the Peter and Paul Fortress which houses the tomb of the Romanoff royal dynasty. We saw the bronze horseman statue (I would highly recommend *The Bronze Horseman* book by Paullina Simons) In the afternoon we visited the Hermitage, and saw paintings and statues by Da Vinci, Michelangelo, Van Gogh and Picasso.

Monday 15th July started with a morning of leisure on the boat. In the afternoon we visited Pushkin (Catherine's Palace). This was burnt down and completely destroyed by the Germans during the siege of Leningrad, which took place during the 2nd World War. The Hermitage is in the centre of St Petersburg, and stayed in Russian hands, so it remained relatively intact, but Catherine's Palace is quite a distance away from the city in an area which was under the control of the Germans. The palace was restored to its original glory by the Soviet government, so that we can now appreciate it as it was. This palace gives us an idea of the opulent lifestyle which the Romanovs enjoyed.

We had an early start on Tuesday 16th July, so that we could visit Peterhof (Summer Palace) This also was destroyed by the Germans and had to be restored by the Russians. Although the house was magnificent, it was overshadowed by the gardens with its ornamental fountains, which was built by the Tsar who wanted it to be more magnificent than Versailles in France.

Wednesday 17th July, and sadly it is time to return home. Despite what you hear about Moscow and St Petersburg not being safe places to visit, we found it to be very clean, safe, and the people to be very friendly.

Maureen Wilcox

Has anyone heard of Expert Patients Programme?

History and background

The Expert Patients Programme (EPP) course was first devised and developed at Stanford University, California, in the 1970s; it was initially known as the Chronic Self-Management Programme (CDSMP).

Several assumptions underlie the CDSMP programme.

People with long term conditions have similar concerns and problems.

People with long term conditions must deal not only with their condition(s), but also with the impact their condition has on their lives and the lives of family.

Lay people (volunteer tutors) with long term conditions, when given a detailed tutor's manual, can teach, as effectively, if not more effectively, than healthcare professionals.

The process or way EPP is taught is as important, if not more important, than the subject matter that is taught.

In a five-year research project, the programme was evaluated in a randomised study involving more than 1000 subjects. This study found that people who went on the programme, when compared to people who didn't, improved their healthy behaviours (i.e. Symptom management, coping with low mood and depression and communication with health care professionals), and decreased their days in hospital and their number of GP visits.

The Department of Health bought a licence from Stanford University and brought the courses to England in early 2002 and a number of Primary care trusts (PCT's) were asked to pilot the course.

More details about whether courses are available in your area can be found at

www.expertpatients.co.uk

For Wales check out

www.wales.nhs.uk/sites3/home.cfm?orgid=537

What is an Expert Patients Programme?

A self-management programme for anyone over 18 with a long term health condition to help you learn to –

- Manage your symptoms
- Improve how you feel
- Deal with anger, fear, frustration
- Deal with isolation and fatigue
- Deal with depression and anxiety
- Manage pain
- Plan for your future
- Work better with your health care professionals
- Develop the confidence to take more control of your life
- Improve communications with family, friends and professionals

The course also gives you ideas and techniques about

- Relaxation
- Better breathing
- Healthy eating and nutrition
- Basic exercise – how to build your strength
- Problem solving skills
- Positive thinking techniques
- Setting goals
- Being realistic about impact of your situation on yourself and your family

An insider's view of the Guillain-Barré syndrome

This is a personal account of my wife's (Helen) and my recollections of the events of my own experience with GBS. It was put together initially for our own benefit, then later upgraded into a more suitable form to pass on to a relative of mine who has occasionally encountered the disease during her nursing career. My experience seems to differ radically from those which I have read in your magazine as I was home and mobile with a stick in five weeks from entry into hospital.

The progress of my illness was rapid and severe while one other I have met had a slow onset beginning with his fingertips and slowly moving up his arms, then his legs. His breathing was quite unaffected possibly because his hospital treatment began before full development. Based on this survey of two, it would seem that the more rapid the development of the syndrome, the more severe it is and the more rapid the recovery. This was confirmed later during a 'phone call to the GBS Support Group which also produced the statistics that there is a 4% death rate, 80% of patients recover completely but can take as long as three years, and the remaining 16% are left with some loss of balance or restricted mobility.

I was first aware of a problem during the nightly excursion when my legs did not function properly and I had to hold on to furniture, door frames and banister rail. How much had I had to drink? – nothing (unusual, but true), very odd. The morning was much worse. It was also the morning that I had an appointment for laser treatment on my right eye. Helen made rapid 'phone calls to the surgery and the Eye Department. At the surgery Dr.O'Donnell (we had seen her the previous day regarding a chest infection we had both picked up on the flight back from Calcutta) who could get no tendon reflex reaction from either my knees or ankles, admitted it was outside her experience and composed a note to the Emergency Assessment Unit at Southport Hospital. We were sent on our way in our own car as it was quicker than calling an ambulance. I remember being wheeled into A&E and then into an office but not much after that except for a loose jumble of fact (events confirmed by others) and hallucination (events confirmed by nobody) between periods of nothing.

The syndrome struck on 4th May a week to the day after our return from Bhutan and India and it set off immediate alarm bells in both the surgery and the hospital; was it something highly infectious I had picked up? I was in isolation until the true nature was established which took about 24hrs. Apparently, I was conscious and coherent for a couple of days but my memory of this period has been largely wiped. During this period Helen consulted the GBS website and was reassured by the information that most patients recover completely, even if it were to take a couple of years.

The inability to breath properly caused, naturally, the most concern. I am told that I was thrashing about and continually knocking off the oxygen mask. Blood pressure was sky-high and facial colour unsurprisingly was not good. At 4.45am of the fourth day Helen received a 'phone call telling her that the staff of the Critical Care Unit could no longer cope and I was to be put on a ventilator. Would she come in – she and our daughter, Lorna, did. It must have been some traumatic experience.

After breakfast Pam (our daughter-in-law) took over from Lorna. At a later stage Helen had another call requesting permission to drill a hole in my throat to fit a snorkel (tracheostomy). This deprived me of any means of oral communication when I regained consciousness.

It seems that I was either naturally unconscious or in an induced coma for 4 or 5 days which was much longer than I initially thought from guess-reckoning. I assume that I had been so filled up with antibiotics and coma-inducing drugs that reality took a second place. Some of the hallucinations were extremely convincing.

My first non-hallucinatory (I think) recollection was the Head of Department asking, "do you follow the procedure?" and "are you scared?" I can recall nothing of his description (Helen thinks this was when the lumber sampling was described). My next recollection (confirmed) was our son, Malcolm, telling me that the basket on the end of my nose carried all my life support mechanism, "Do not touch it." "Eeh?" "I SAID, DO NOT TOUCH IT!" Clearly, I was not at my most coordinated. It took me some time to realise that I was completely plumbed in to my bed. All my input requirements and medicines went up my nose or into my arm, what the medical team wanted was extracted from my right forearm or by wires taped to my chest while what none of us wanted was extracted from elsewhere and piped into a plastic bottle; pick up thy bed and walk, nothing – unplug it and get pushed!

Some of the more interesting hallucinations were being convinced that my life support was a line of fish hooks embedded into my right forearm and trying to unzip them, that there was a railway station attached to the hospital so that emergencies could be brought in quickly (I saw the ticket kiosk and trains arrive so it must be true!), that there was a branch of Tesco on the site (why can't you nip along and get me a couple of yoghurts?) and that the intensive care facility was in some sort of drapery warehouse because there were boxes everywhere and ladies packing them. Having been transferred to the general ward on either 22nd or 23rd May I woke up one night to find it had been reorganised as a laundry-cum-dyeing facility like the one in Dick Lester's film "The Three Musketeers". By the following morning the staff had worked wonders and it was back to normal. Just how long does it take for the last residual droplet of hallucinogen to be flushed through the body?

Once I rejoined the world, the physiotherapists demonstrated the limitations of my hand/eye coordination and the helplessness of my legs. They suggested some useful hand/leg exercises which could be done in bed, clenching toes and fingers, bending feet, knees and hands, bending neck and back. I was exceptionally lucky with the physiotherapists I had as I was made to feel that I was part of a team I worked with, not a patient to be worked on. Their introduction, "We are the physioterrorsts" told me instantly that these were people I could work with. Whatever we tried was just over the border of my capability at the time (I was pushed, good teaching practice) and as I became more aware of my limitations, if there was a direction I wanted to go, we went. I found it surprising that my ability at the beginning of each physio session started exactly at the point that the previous had finished; it was a continuous development, not moving in fits and starts.

As my lungs had been working on oxygen assist for some time they now had to be acclimatised to function on normal air. One day, "Just breathe normally for two hours." The following day, the exercise became "Now we want you to do it for four hours." As I had no other pressing engagement, it received all my attention. The first five minutes were spent establishing the breathing pattern so that I was neither gasping nor holding back, then maintaining that steady pace whilst watching the clock hands hiccup round for the next 3hr55min, staying as still as possible – at least drying paint can be smelled!

Most of this took place while I was speechless and various means of communication were attempted. At this time I had my own personal nurse (I was later given the comforting information that for a few days I had the highest dependency rating in the hospital) and the most effective way of gaining her attention was to circle my hand over my head. This proved quicker than the usual sideways wave or just raising a hand. I guess I was lucky to have arm mobility, if not full leg. The alphabet large-printed on to an A4 sheet was used to spell out laboriously short sentences but this was hampered by my lack of hand/eye coordination and some people trying to guess the word on the third letter. Irritating but we usually managed.

Then the day the tubes were removed – I could speak and had to be conditioned for normal eating and drinking. Firstly, the diaphragm had to be

checked for coping with liquids and then solids – for the latter, everything liquid was treated with a jellying agent; ever had jellied tea? – don't if you can avoid it; jellied apple juice was far more palatable. Then there were meals of pulverised food where the last mouthful tasted exactly the same as the first, nourishing but boring. Later, I was encouraged to have between-meal snacks which visitors could take in; I wanted a chunk of our local butcher's pork pie and chilled Highland Spring Water – so much for a hefty shiraz or a malt.

At that time transfer out of bed on to chair or commode had to be done by hoist but as communication with the physiotherapists became more meaningful, "was there any direction which the therapy could usefully go?" Having experienced the delights (----!) of toilet facilities for the seriously disabled, you bet there was a direction – I wanted to be able to walk to the loo! This was fully accomplished in the morning of my last full day 5th June. There was nobody around so I did everything I wanted without assistance or supervision. As I emerged I was confronted by the chief physiotherapist who was eyeing up the empty bed, empty chair and the abandoned zimmer and an expression on her face, "where the ---- is he?" I had a rocket for ignoring the Health and Safety rules (falling over is not worth the paper work), said I had achieved my aim and my reply was therefore in two parts; part 1, my humble and grovelling apologies, part 2, YES!!

But first I had to be taught how to stand up from a sitting position, initially, trying to use legs which were too weak to support me. As strength developed, getting to a standing position was achieved on the second day's attempt (bloody-mindedness compensating for lack of confidence), became easier, then a slow, wobbly shuffle with a zimmer became possible. This took two and a half weeks. Many days I had two physio sessions firstly at 10am, recovering just enough for the second at 3pm which was exhausting, but successful. The zimmer was also useful as a transfer tool to get me from bed to chair, the hoist no longer being needed. Also to the commode which in turn was used to transfer me to the toilet and then the zimmer from commode to toilet then, naturally, the return journey; it was all very labour intensive. My first proper excursion with the zimmer was along the length of the ward with all three physiotherapists in attendance, Amy and Liz on either side to catch me if I fell sideways and Andy behind me pushing a chair. I did seem to be monopolising the physio resources but their response was, "if it's on offer – use it". When all this was accomplished I was transferred to the Rehab ward at Ormskirk Hospital on the 31st May. By chance, Andy was seconded to Orsmkirk so during any free time he gave me finger massages with a rough towel until my middle finger began to twitch, apparently this was a sign of progress. My stay there overlapped the Jubilee weekend and as the physio people were on holiday, I spent as much time as I could practising with the zimmer and doing leg exercises on the bed and off. When they returned I was able to walk a few yards holding the zimmer off the floor. That same day we established that I could walk along the corridor with a stick and climb stairs, also with the stick. My reign of disruption there came to an end on 6th June.

After being at home for a couple of weeks I was confident enough to walk to the local newsagent with Helen riding shotgun and after another week, on my own carrying the stick and my mobile in case I had to be retrieved. We walked into town and back one day (about 3 miles) and two weeks later walked along the first sea embankment, to Crossens village and back home (about 5 miles), stopping for a welcome sit down and a celebratory ice cream in the Botanic Gardens; the next two days were spent recovering. During our first excursion to Liverpool on the 7th August I found my fingers had at last recovered sufficiently that I produced a near legible signature, i.e. normal. On the 27th August I found myself walking the long mile to Churchtown for the newspaper and for the first time walked the whole way at more or less normal speed without too many wobbles. It was soon realised that what had been mundane was now a mile-stone; pulling on my trousers whilst standing, carrying a mug of tea up the stairs without holding the banister.

The early morning stiffness in my legs went, returned and vanished, I hope permanently, just before Christmas.

I found it surprising that I seemed to accept immediately that my life for the foreseeable future was in hospital and therefore there was no point in worrying about home and when the time did come to leave, I left. Also, I lost interest in music and TV (fortunately, these have returned) but compensated by reading nine books. I watched some of the Paralympics on TV realising that by comparison, my problems were a mere pimple on a mountain range and that I was well over the hump to recovery.

Obviously, I was unfortunate to be affected by the Syndrome but from then on I was extremely lucky, firstly by seeing the same doctor at the surgery on two successive days when the deterioration in my health was obvious. I had just returned from India and therefore had the undivided attention of the hospital team who had to establish, firstly it was not some variant of the Black Death. Once it was realised (a) it was not contagious and (b) what it was, I was rapidly given the required medication and care. The physiotherapists were excellent, invariably getting me to work to my limits. The Social Services care was also extremely good but fortunately we found that the only services needed were providing a leaflet of useful exercises and fitting two grab-handles over the bath as by then I was able to perform the other tests they requested. Fortunately, again, I did not need an additional rail up the stairs as a white plastic pipe would have ruined the décor! Finally, I think, Helen was extremely relieved when she realised she did not have this amiable, sweet-natured, cooperative soul as an invalid for a lot of months!

B R Chamberlain

Books

Faith, Angels and Overcoming GBS: The Jim McKinley story

by Jim Mckinley and Paul Funk, Jr

Available through Amazon, B&N and westbowpress.com.

Jim developed GBS in a flash one morning as he readied for work. He was misdiagnosed as having a stroke and given medications that didn't help him. By the time he was correctly diagnosed, the window for helping him had closed. It took several years before the coma like state he entered went away. Afterward he recounted many spiritual events. The most powerful is that of seeing an Angel.

Throughout this entire ordeal Jim kept his composure and "happy go lucky" attitude. He shares many wonderful things with readers including a journal and log book kept by family and friends during the years of his incapacity. Jim is a fine example of how GBS can be overcome.

Sharing my experience

My name is Cecil Isham and I am 86 years old and I would like to share my experience of the Guillain-Barré syndrome. It all began of the 3rd May 2013. I was looking forward to spending a week with my daughter in Scarbourgh, my wife had recently died in March and we had been looking forward to our diamond wedding anniversary in June. I have always been independent, caring for my wife, shopping, cooking, etc. However on the 2nd May 2013, I felt quiet unwell. I had sickness and diarrhoea and was unable to go to Scarbourgh, so my daughter stayed with me. Two days later, I began to feel a little better, but that evening I suddenly felt dizzy and my legs went from under me. I fell to the floor, fracturing my hip. My daughter had left me only a few minutes earlier, as I said I was feeling better, and that she need not stay the night. I laid all night on the floor in agony, unable to move or call for help. My daughter found me the next morning, and raised the alarm. When I got to hospital, I was assessed and told that they could not operate until I was clear of the sickness and diarrhoea virus.

On the 8th May, I was considered fit enough for surgery, all went well but two days later I could not feel my feet. I was unable to get out of bed and I had no strength in my legs. The next day I was unable to move or feel my arms, and my whole upper body was numb. I was given a lumber puncture test, and was told that I had GBS. I was then moved to intensive care, as my breathing had become difficult. I was given a 1 week course of immunoglobulin and nerve tests. I was also unable to swallow, so I had to have a tube through my nose, as eating was impossible. I laid there wanting to die, I felt helpless and missed my wife. I wanted to give up, but my daughters would not let me. After two weeks in intensive care, I was moved to a rehabilitation ward. I started to get pins and needles in my hands, and a little movement in my fingers, though I could not hold a pen. My upper body strength slowly started to come back over the next two weeks, but my feet and legs were heavy. I had a goal to aim for, my daughters had recently claimed my war medals in January, and I was to be presented with them on armed forces day in Huntingdon on June 28th. The physiotherapists were encouraging me all the time, but the day before the presentation, I was quiet weak and could not get out of bed. I was not sure if I would be able to go, but the next morning I felt much stronger, and I was given the all clear to go. My daughters arrived at 9am to help me get my suit on, and the wheel chair taxi arrived at 930am, to take me to the ceremony. It was a very emotional time. At 1230 I arrived back at the hospital. I felt I had a renewed strength and a will to get better. 10 days later, I was fit enough to go to Rehola care home in St Ives, as I could now walk with a frame, but my feet were heavy and spongy.

On July 23rd 2013, after 2½ weeks, I was discharged from Rehola and have been at home now for 3½ months. My feet are much better now, my upper body strength has returned to normal, although I need to use two sticks for support as my hip is still weak as I was unable to do physiotherapy due to the GBS. I don't know if it was the sickness virus that caused the GBS, or the trauma of the surgery, or both, but I know whatever the cause was, I beat it and am now living life to the full, albeit a lot slower.

Cecil Isham

Lewis Sumner syndrome – the long haul to diagnosis

March 1999 – It was Sunday morning. My husband was working abroad and I was due to go and collect my daughter from university for the Easter holidays. I woke up with severe tingling in the thumb and first three fingers of my right hand. I shook it hoping it would go, but after about 15 minutes it was even worse and I realised something was wrong.

By mid-morning my hand had a more numbish feel and pain had developed through the length of my arm and into my shoulder blade, and it was getting steadily worse. I took the car for a run round the block to check that I still felt safe to drive, then rang my daughter to tell her I would be leaving straight away, earlier than planned, in case it got even worse. It was only an hour's drive and as soon as I arrived, we quickly loaded the car and set off home. Driving along the M25, the pain was becoming sickening and I had to pull off at the services and ask my daughter to take over.

Back home, I rang A&E and was told that it sounded like carpal tunnel syndrome, but they would only be able to provide stronger painkillers, and I should see my GP in the morning. I couldn't face a long wait in A&E, so I relied on the pain killers I had at home – they didn't help.

The next morning, my GP thought it could be carpal tunnel syndrome, but because it was so sudden and severe, referred me straight away to an orthopaedic surgeon 'to get the ball rolling' and prescribed some stronger pain killers. My appointment was to be four weeks later.

I struggled through the next week as my hand became next to useless. Simple things like getting dressed, showering, and eating had to be done using my left hand alone. By Easter weekend, I was pacing the floor at night, unable to sleep with the pain and I returned to my GP first thing on Tuesday morning. He took one look at the weakness and deterioration in my hand and phoned the hospital asking for my appointment to be brought forward. I was told to get myself straight to hospital where a different consultant who usually dealt with lower limbs rather than hands, would see me in half an hour. He thought because of the severity, that the median nerve might have been trapped in my neck. I was sent to physio to be fitted with a collar and sling and referred for an MRI scan the following day. This showed bony bars on a couple of vertebrae although they didn't look as if they ought to be causing so much trouble. The physio attempted to relieve any pressure on the nerves in my neck, but decided after a few days that it was pointless as there was no improvement. I was sent for nerve conduction tests which were performed by a very enthusiastic neurophysiologist with his exclamations of 'amazing!', 'a triple peak!' and 'how extraordinary!' The problem was close to my wrist on the median nerve, but clearly not straight forward carpal tunnel syndrome.

Soaking in a hot bath was the only thing that brought any relief. One day I stayed there too long. I was desperately tired, on lots of medication and I tried to get up too quickly. Everything went black and I knew I couldn't get myself out, so I shouted for help and hurriedly pulled the plug. The bathroom door was unlocked as I couldn't turn the key. My husband 'caught' me just as I began to collapse, but I was slippery with bubble bath and he couldn't hold me upright, so he slid me down the wall from which protruded a fixed soap dish – Oh the bruises when I came round! To his horror, my seventeen year old son was called upon to help get me out of the bath!

I wore a glove most of the time as even a slight draught across my hand caused agonising pain. I had sensations of burning, crushing, of maggots crawling all over my hand, of my hand being drilled through and extreme hypersensitivity. Sometimes it felt as if my hand was wrapped in stinging nettles. I began to loathe the dawn chorus which signalled that another day to be endured was beginning, when I hadn't yet been to sleep. I moved to the spare room downstairs so the rest of the family were not also deprived of sleep. In the lonely early

hours when the pain was always at its worst, I had thoughts of demanding amputation, but the thought of phantom limb pain made me think again. I didn't know how I could live which such pain for much longer although I still desperately hoped that my next appointment would result in relief. Thoughts of overdosing crossed my mind, then I thought of who would find me – maybe my son – I couldn't do that to him – I had to get help and fast. My husband knew that I was becoming desperate and impressed this upon the orthopaedic consultant at my next appointment. He said although there was no guarantee, a carpal tunnel release might take pressure off the nerve and bring some relief. I agreed and he added me to his list for the next day.

The operation was performed under general anaesthetic because the consultant was worried that the hypersensitivity would cause me to pull my hand away at the slightest touch. When I woke up, the nurse asked me if I had any tingling in my fingers. I saw the funny side and told her she would have to find another way of checking that the bandage was not too tight! I was disappointed but not surprised that the tingling was still there. I clung to the hope that at least something had been done and hoped it was a turning point.

Three weeks later, my stitches were removed, an unreasonably painful procedure. There was some improvement in the neuropathic pain, but my fingers had become stiff, the muscles of my hand wasted and I was barely able to move it. The consultant said I had Sudeck's atrophy and I was about to experience one of the cruellest but kindest acts of my life. He wrapped his hand around mine, forced it into a fist and held it there for an age! It was excruciating and my husband thought I was in danger of using my left hand to throw a retaliatory punch! I was told that if I didn't work through the pain and work very hard with physio, I would never use my right hand again, then he marched me round to physio with instructions to 'bully this lady and get that hand working again'. I had no intention of giving up on my right hand and now I knew that causing pain didn't necessarily mean causing more damage. I was prescribed tegretol which brought me out in a rash and had to be stopped. I was referred to a neurologist and had further nerve conduction tests, but it was still unclear what had happened.

I had physio for an hour every day at first and exercises to do every two hours at home, and yes they hurt, but the improvement was noticeable by the day. I felt such a sense of achievement when I was able to touch my thumb and index finger together, but disbelief when I realised that I should be able to touch my thumb and middle finger as well. A few days and more pain later, I could, and then the next finger had to be worked on. I gradually began to appreciate the range of movements our hands are designed to make and how easily we take them for granted. I was introduced to therapeutic putty and digi-flex to rebuild the muscles in my hand. I stroked fabrics with different textures to stimulate sensation. I rested my hand alternately on a bag of frozen peas and a hot water bottle to stimulate circulation. I practised turning taps on and off, wringing out flannels, turning over newspaper pages, turning keys in a lock, tying shoelaces, using cutlery. I practised drawing loops and squiggles with a pen, then rows of eees and mmms etc. Eventually I could write something vaguely resembling my signature – a real milestone. Progress was slow but steady. Sometimes I tried to do too much too soon like when I decided I was able to cook the dinner unaided, but finished up dropping the curry in my husband's white trainers which he had left beside the cooker. I was banned from the kitchen for a little longer.

After ten weeks, I was told I could drive again and was able to return to work. The tingling has never gone and some level of weakness remained, but over the next couple of years I got used to the strange sensation of my hand and learned to ignore it and bit by bit I regained more power. Eventually there was nothing I couldn't do either myself or with a simple gadget. No one could explain what had happened and we all hoped it was a 'one off'. I put the whole episode behind me and was truly grateful for the fast action of my GP, the bullying and encouragement of the orthopaedic surgeon and the physiotherapist, and the help and support of all those around me.

August Bank Holiday 2001- I was ironing a blouse before going out and noticed a

strange sensation in my little and third finger of my right hand, then the tingling set in, then numbness. I tried to ignore it but I was worried. My GP referred me back to the neurologist and nerve conduction studies confirmed a problem with the ulnar nerve. I was tested for HNPP (hereditary neuropathy with liability to pressure palsies). The results took weeks to come back and were negative. Symptoms were mild and after six weeks, I seemed to have made a full recovery.

In mid-November, I awoke one morning with that awful intense tingling I recognised from over two years ago. My right ulnar nerve, that had played up a few weeks before, was to follow the same course as the median nerve had done – tingling, then numbness, and pain along my arm for the first week. Then burning and hypersensitivity in my hand as the numbness wore off. It became steadily worse for the next three weeks, still horrible for about six weeks, then gradual improvement over several months, but normal sensation a thing of the past. My GP prescribed amitriptyline which took the edge off the pain and helped me sleep, and sent me straight back to the neurologist.

Two days later, a patch on my knee became numb lasting two days. Another nine days and the sole of my left foot felt strange and a few days after that the same thing happened to my right foot. I felt as if I was walking around on socks that had been rolled up and stuffed into my shoes. Six weeks later, I was watching TV when I had sudden pain in my left forearm. Over the next couple of minutes, tingling travelled down my arm to my wrist. The medial cutaneous nerve was under attack. I also had a strange sensation in my right leg. As advised by the neurologist, my GP immediately prescribed a short course of steroids. Uncertain of the most appropriate dose, I was started on 30mg/day. The flare up followed the usual pattern but was a little less unpleasant than the previous two. I was hopeful that steroids were the treatment I needed.

I was told I had mononeuritis multiplex, most likely caused by some form of vasculitis. I was referred to a rheumatologist who did numerous blood and urine tests and a chest X-ray. Churg Strauss syndrome was a possibility, since I also have asthma and high blood pressure, but these were thought to be red herrings since my asthma started thirty seven years earlier when I was eight, and I have a family history of high blood pressure. All the tests were normal and there was no sign of systemic involvement. Only the nerve conduction tests were abnormal, showing demyelination and axon damage. I was closely monitored for any signs of systemic vasculitis for the next four years.

Just two months after that first course of steroids, the ulnar region of my left hand showed all the signs of another attack. This time I was started on 60mg/day prednisolone. It was a nasty attack but not quite as bad as it had been with the right hand. Again I rested my hopes on steroids.

My local neurologist began a series of referrals to various London hospitals. Nerve biopsy was on the cards, but he didn't feel that my local hospital had the specialised laboratory back up needed for the procedure. With my sural nerves still relatively undamaged, no one wanted to biopsy them as the chance of a meaningful result was not high and it risked causing permanent neuropathic pain. At the first London hospital, the decision was made to biopsy a small sensory branch of my right ulnar nerve which was already significantly damaged, but it was delayed by an attack on my left radial nerve, just five months after the last short course of steroids. This time I was prepared with steroids at home. I started on a dose of 60mg/day within half an hour of the onset of symptoms, enough time for me to be sure it was not a false alarm. The symptoms were milder than with previous flare ups and recovery much better. Normal sensation eventually returned to that area of my hand.

After I had been off steroids for a couple of months, it was decided that the nerve biopsy could go ahead. It was a bad day and a waste of time. My allergy to latex was clearly on my notes and I tried to make sure everyone was aware of it, but communications broke down and no one told the theatre staff. When they saw my wrist band, they went potty and the operation was delayed by a panic to find latex free gloves for the surgeon. Apparently there were none in his size in the entire hospital and he operated in a pair half a size too big! I was already stressed after a long journey from home in heavy traffic and being admitted by a nurse whose understanding of English was extremely poor. In spite of a sign saying 'Nil by mouth', I was offered sandwiches three times which drew attention to my empty stomach. Then the window cleaners turned up just as I was asked to change into a gown. During the operation, I had to ask for an extra shot of local anaesthetic and I was aware that the nerve was proving difficult to find. Eventually a piece of something was removed and I was wheeled to the recovery room where the admission nurse and theatre technician began arguing across me over whose fault it was that theatre staff hadn't been

informed of my latex allergy. I just wanted to go home, but I had to wait several hours because my blood pressure wouldn't settle down!

A week or two later the result of the biopsy came through – the tissue sample was connective tissue, not nerve. I fought back the tears and politely refused a second attempt at biopsy of the same nerve. My local neurologist agreed with my decision.

I was convinced that my illness whatever it was, responded to steroids, a short course of which kept me free of attacks for between three and five months. By now several of my nerves were damaged and strange sensations came and went, or worsened and improved. It was difficult for me to know whether it was due to slow progression of my illness, or just fluctuations in damaged nerves. My neurologist decided to put me on steroids for a longer term to try to prevent further flare ups.

The steroids made me feel muzzy headed all the time and I was having difficulty sleeping. I was permanently tired. Trying to work and keep things ticking over at home was becoming increasingly difficult and I felt that I was just getting by from one day to the next rather than living my life. I was feeling depressed and resentful and that I was on a slippery slope that I did not want to go down. Over a bank holiday weekend in May 2003 when I was feeling particularly low, my husband suggested I should write a resignation letter for work so it was ready if I decided to use it. I wrote it and used it first thing on my return to work and felt that a huge burden had been lifted.

Almost a year later and still with a nerve biopsy in mind, my neurologist referred me the National Hospital for Neurology and Neurosurgery. I was seen by a consultant neurologist and several junior doctors who came to observe 'this interesting woman'. A familiar pattern was emerging. When my medical history was taken and I was examined, it was generally agreed that vasculitis, probably a nerve specific form, looked most likely although no markers were found. Nerve conduction studies were inconclusive and caused opinion to become divided, some agreeing with the vasculitis school of thought, others thinking a variant form of CIDP the most likely culprit, but nothing seemed to really fit. A persistent nerve block in my right wrist seemed to support the CIDP theory. Horror of horrors, it was thought that a lumbar puncture might prove useful. I am not usually squeamish, but I have an irrational fear when it comes to needles being stuck in my back. It was a horrible ordeal for me and as my CSF was normal, I hope they won't need to do that again!

To further confuse matters, I developed episcleritis and although the ophthalmologist did not think this had anything to do with vasculitis, it did cause some concern with Churg Strauss syndrome and treatment with cyclophosphamide briefly being reconsidered.

I had become used to my illness having no name and was reassured by the knowledge that it responded to steroids and that amitriptyline helped with the pain and sleeplessness. I also knew that other options could be tried if necessary. I just told myself that I was a girl in a million and joked that perhaps one day I might have a disease named after me.

When I was seen again at the National Hospital, my condition was stable and my symptoms were mainly sensory and relatively mild. Their advice was to treat the neuropathic pain, but not the disease because of the long term side effects of the steroids. I had been on them constantly for three years and they were slowly reduced until I was off them completely. After a further six months of stability, I shook hands with the neurologist in my local hospital as he discharged me from his clinic saying that he hoped he would not have to see me again too soon, perhaps not for five years.

July 2011 – Four and a half years later, I woke up with that familiar intense tingling in my right hand – the ulnar nerve yet again. I was prescribed 60mg/day prednisolone and amitriptyline by my GP. A few days later my left foot began to feel strange, then after another few days, my right foot. Pregabalin was added to my medication when I saw the neurologist three weeks later. Blood tests and nerve conduction studies were to be repeated. The usual pattern of numbness, pain, muscle wasting and weakness took its course.

This time, the nerve conduction tests were done in the Atkinson Morley Wing at St George's. They took over an hour and turned out to be the most thorough I had ever had and included EMG with needles stuck into my hands and feet for the first time. My husband sat at the end of the couch chivvying me along as I twitched and winked at him. When the results came through, the neurologist who had previously been of the vasculitis school of thought, told me that the diagnosis had changed and that IVIg treatment might help. He referred me to a neurologist at St George's who told me that I have Lewis Sumner syndrome and explained that I had probably had a virus, bacterial infection or allergy to something and that my nerves were being recognised by my immune system as similar to the coating on the virus or whatever it was. It was the most plausible explanation I had been given and the first that was not preceded by the words 'it might be'.

He went on to explain that treatment would be aimed at preventing further attacks since motor nerves are involved. The worst of the nerve damage is in my right brachial plexus with the worst effects in my right hand – as luck would have it I am right handed! I was started on azathioprine so that the steroids could be reduced and told that IVIg would be reserved for me if I have any more relapses. Another two years on, I am in remission, and the azathioprine has been reduced to 25% and allopurinol added to enhance its immunosuppressive effects, whilst reducing the adverse effects on my liver.

Both myelin and axons are damaged in my nerves and I have been told that what I have lost is permanent, and that if there is any improvement, it's a bonus. I know this is largely true, but I also know that where there is still some nerve stimulation, hard work and determination can sometimes, to some extent, rebuild those wasted muscles. The process is long and slow, but the benefits are worth every effort and every moment spent trying.

So nearly 13 years after I became aware of the first symptoms, my disease finally had a name. It has stuck for two years, so now I confidently say 'I have Lewis Sumner syndrome'.

Cecilia Cole

Useful Gadgets

If you have found a useful gadget or item that would be of interest to others, please forward details to fundraising@gaincharity.org.uk. Our thanks to Celia Cole for sharing the following:

Brabantia Universal Opener – fits most bottle and jar lid sizes. Useful for opening bottles of milk and soft drinks, and even bottles of household cleaners with childproof lids that have to be sqeezed on opposite sizes and twisted at the same time.

http://www.brabantia.com/uk/universal-opener-stainless-steel/

Also available on Amazon and at Robert Dyas.

J-Popper Ring Pull Can Opener made by BRIX of Denmark – Great if you can't grip a ring pull firmly enough to pull it back.

http://www.brixdesign.com/413/j-popper-ring-pull-can-opener

Available from Amazon

JarKey made by BRIX of Denmark – Lifts the edge of the lid which releases the vacuum so it is much easier to unscrew the lid.

http://www.brixdesign.com/403/about-jarkey

Available from Lakeland and Amazon

http://www.lakeland.co.uk/7706/Jarkey

News from the Branches

Midlands

The Midlands meeting was held on 28th September 2013 in Harlaston Village Hall being a beautiful Saturday afternoon. Some members took advantage of the location and called in at The National Memorial Arboretum in Alrewas, which was only 3 miles away and is well worth a visit.

The meeting began at 1pm and a delicious lunch was provided for all. The gathering gave everyone an opportunity to meet new people, share experiences and catch up with old friends.

A GBS raffle was held and raised over £100. Some dedicated members had made jams and pickles, cakes and greeting cards, all to raise money for this very worthy cause. A succesful and inspiring afternoon was had by all.

Thanks go to everyone involved in arranging the meeting and providing the scrumptious buffet lunch!

Kent

The Charity Day 2013 was a very good day raising just over two hundred pounds. Fifteen charities plus the Friends of St. Nicholas Church were there and thankfully the sun shone, which always helps.

Due to illness, the Post Christmas Lunch on 4th January was sadly depleted. Nevertheless, 8 of us sat down to a very enjoyable lunch organised by Ray Ponsford and John Larkin. It was good to meet up, exchange news, and to renew friendships.

We are hoping to organise the next meeting for early Spring, possibly in March.

Scotland

The Scottish Branch held their AGM Conference on Saturday 5th October at the Holiday Inn Hotel, Glasgow Airport. There was an excellent turnout for the meeting. This year the Branch had an additional Prize Draw for a holiday donated by Mr & Mrs T. Shaw, Isle of Bute, which raised the sum of £480, which was won by Mrs. E. Edgar, 2nd Prize a bottle of whisky won by J. Kelly, and the 3rd Prize Argos Voucher by T.E. Brown.

Christmas Card sales exceeded expectation with a total sell out, with some monies still to be received, raised £286.

This year's raffle included a donation of a knitted Nativity Scene from Mrs. Nancy Shaw, Argyll, which helped to raise the £81 for the raffle on the day. Many thanks to everybody who donated prizes.

The speakers were Professor Hugh Willison, who gave an overview of what was happening in the research lab in Glasgow and Dr Govind Chavada, who updated us on the progress of the IGOS 1000 project which has taken off around the world with resounding success. Over 300 patients are already included, with a high proportion of these being recruited from UK centres. Dr Amy Davidson discussed a new clinical trial that she is coordinating in Glasgow that aims to reduce the inflammation in the peripheral nervous system in the early stages of GBS. James Babington Smith spoke about the new charity and revealed the new name and logo for the support group which should be starting from the February 2014.

The next Scottish Branch AGM will be held on the 4th October 2014, again at the Holiday Inn, Glasgow Airport.

South West

The next meeting is at Saltford Golf Club, Bristol on Saturday March 22nd from 2.00 till 3.30, followed by tea and biscuits. Caroline Morrice, Director, will be joining us with news from head office.

The golf club's restaurant will be open, and you may ring the bar on 01225 873513 and book a table. Please give them 1 week's notice. There will be a raffle and prizes will be very welcome. The cost for this meeting will be £2.50.

Yorkshire

The Yorkshire branch meeting was held on 13th October 2013. We had to cancel the March meeting at the last minute after a few days of heavy snow and were all happy to be able to meet again.

Doris Fryer opened the meeting and welcomed our two guests – Julie Laws and Caroline Morrice. Julie talked about the Kirklees expert patient programme including how it was organised and what benefit it was to patients with long term health problems.

Caroline gave us an update on the office news and the work of the board. This was followed with a question and answer session including some useful information regarding GBS patients and the DVLA. We then had a break for refreshments and a chance to chat with old freinds and our new members.

Longstanding member Eric Snowden who is also president of the Yorkshire association of golf club stewards presented Caroline with a cheque for £500 they had raised for us. Caroline and Julie were presented with a small thankyou gift by Heather Brophy.

We had 11 apologies from those unable to join the 47 of us who attended, including 7 new members.

We did very well financially due to the generosity of all at the meeting. Collection and coffee money came to £109.88, the raffle raised another £32.40, sales of group merchandise totalled £35.45, the Christmas card stall sales came to £133.00 so with the cheque, it all totalled £810.93 – a magnificent sum, thank you everybody.

The next meeting will be on 23rd march 2014, weather permitting!

Lancashire and Cumbria

2014 Meetings – 2.00pm – Bilborrow Village Hall, Bilsborrow

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

A full copy of the Lancashire and Cumbria newsletter is available on our website

Letters to the Editor

Dear Sir,

At the recent meeting of the Kent Group, we put on the theme of What Support is Available for the Carers, as requested by some members, as well as What Support is Available for those with GBS. Two speakers were invited, one for each theme. Until that time, I had no idea of the support that was available for carers, or where to go to look for it.

We learnt that an organisation called Support for Carers, Ashford, which covers a large area of Kent, has been open and staffed by trained volunteers since 1994. This is 2 years before our son, Chris, became severely affected by GBS. At that time we were offered no professional support at all, and it was never suggested that this might be necessary, apart from our very supportive GBS visitor. I am a GBS volunteer for carers/family members, and have not yet been called. I intend to get in touch with our speaker from support for Carers to request some time with her with some up to date guidance on how to provide this support and her criteria for referral.

The purpose of this letter is to bring the need for support for carers and family forward and to find out if there are others who feel that this is a need that is not yet catered for. Also to see what can be done about it in the professional sphere as well as within the Group.

Yours sincerely
Tricia Swift

Wills & Legacies

Our annual income from membership subscriptions and other sources would allow us to make only modest grants to the Charity on a regular basis. Our ability to finance major projects in support of patients and research is heavily dependent on legacies from friends, members and other supporters of the Charity.
Any amount you leave can help and we welcome all sorts of donations left to us in Wills. It is completely up to you what kind of gift you choose to leave:

Residuary Gift A residuary gift is a share of the residue of your estate. This is what is left after family and friends have been provided for in accordance with your wishes. This is a helpful and straightforward way to leave a legacy, as unlike most other donations in Wills its value will not be affected by inflation.
Suggested wording for your Will: *'I give free of inheritance tax x% of my residuary estate and the income thereof to Guillain-Barré & Associated Inflammatory Neuropathies, Registered Charity Number 1154843 & SCO39900, for its general charitable purposes and I declare that the receipt of the treasurer or other proper officer shall be a sufficient discharge to me executors.'*

Pecuniary Gift A pecuniary gift is a stated sum of money – you can choose exactly how much you wish to leave by giving in this way.
Suggested wording for your Will: *'I give free of inheritance tax £x to Guillain-Barré & Associated Inflammatory Neuropathies, Registered Charity Number 1154843 & SCO39900, for its general charitable purposes and I declare that the receipt of the treasurer or other proper officer shall be a sufficient discharge to my executors'.*

Specific Gift Some people might choose to leave us a valuable item, such as jewellery or property. You can outline in your Will whether these items may be sold and whether we can use the proceeds in accordance with your wishes. We understand that personal belongings are very special, and we advise you to get in touch with us if you would like to give in this way so we can discuss your intentions.

What do you need to do?

To leave a legacy to Guillain-Barré & Associated Inflammatory Neuropathies, you simply need to include details of the donation in your Will. If you have already made a Will you can still help **gain** by adding a codicil to your existing Will; this is a supplement to your existing Will and can include new instructions and delete old ones without having to go through the task of revoking the whole Will.

We do advise consulting with your solicitor or legal advisor before completing a codicil form. Please do not write on or amend your current Will, as this could render the Will invalid.

Conference 17 May 2014 Booking Form

Please complete this form and send with payment by 25 April 2014, to
gain Woodholme House, Heckington Business Park, Station Road, Heckington, Sleaford NG34 9JH.

Title | First Name | Surname | Membership Number | GBS/CIDP/Other

Address

Post Code | Telephone | E-mail

Details of those attending If you have any special requirements, accessible room, shower etc please tick box ☐ and state below

Full Name of those attending

I would like to attend a Volunteer Training session on Friday 3pm – 6pm **Yes** ☐ **No** ☐

CONFERENCE AND ACCOMMODATION AT THE VILLAGE HOTEL SWANSEA

Friday 16 May

Dinner, Bed and breakfast *(please enter number of rooms required in box and calculate total)*

☐ **Double Room** @£110 *per room* ☐ **Twin Room** @£110 *per room* ☐ **Single Room** @£90 *per room* = £

Bed and breakfast *(please enter number of rooms required in box and calculate total)*

☐ **Double Room** @£90 *per room* ☐ **Twin Room** @£90 *per room* ☐ **Single Room** @£80 *per room* = £

Saturday 17 May

Conference Deal
Dinner, Bed and breakfast, Conference, Lunch & Refreshments *(please enter number of rooms required in box and calculate total)*

☐ **Double Room** @£200 *per room* ☐ **Twin Room** @£200 *per room* ☐ **Single Room** @£130 *per room* = £

Conference Day delegate *(please enter number attending)* ☐ @ £34 *per person* = £

Dinner *(please enter number)* ☐ *(if you require dinner and you've not booked it as part of one the accommodation options)* @ £18 *per person* = £

Sunday 18 May

Dinner, Bed and breakfast *(please enter number of rooms required in box and calculate total)*

☐ **Double Room** @£110 *per room* ☐ **Twin Room** @£110 *per room* ☐ **Single Room** @£90 *per room* = £

Bed and breakfast *(please enter number of rooms required in box and calculate total)*

☐ **Double Room** @£90 *per room* ☐ **Twin Room** @£90 *per room* ☐ **Single Room** @£80 *per room* = £

Totals

SUB TOTAL £

Local Contact / helpline volunteer discount -£20.00

Total = £

Payment *To be paid at time of booking*

Cheque / Postal Order enclosed for £ Payable to **gain**

Please debit the sum of £ from my Debit or Credit Card

Card number

Issue Number | 3 digit security code | Start date / | Expiry date /

Name as it appears on your card

Signature

Any other infomation

Patron: Air Marshal Ian Macfadyen CB OBE Medical Patron: Professor Richard Hughes MD FRCP FMedSci
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The Charity receives no Government or Lottery funding and relies solely on charitable donations which can be made online through our website or forwarded to the office address.

Thank you

In memoriam

A donation to **gain** is a special way of remembering the life of a relative or friend.

www.gaincharity.org.uk

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