gain4all

SPRING 2015

Issue 5

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

'All smiles' at the first Regional Event (South East). See pages 4-5 for details

www.gaincharity.org.uk

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Lottery

How it works

For just £1 per week you will be allocated a six digit **Unity** lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques issued and posted directly to you, so there is no need for you to claim. You must be 16 or over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

Prizes

£25,000	£1,000	£25	£5
6 digits	5 digits	4 digits	3 digits

By playing our lottery you are directly supporting GAIN and together we can continue to help those affected by these terrible illnesses. Please complete the detachable form opposite or join online at http://www.unitylottery.co.uk/charity/display/guillain-barre-associated-inflammatory-neuropathies

The Unity Lottery, Barrow-in-Furness, LA14 2PE T: 0870 050 9240 E: info@unitylottery.co.uk

Results and Rules can be checked by visiting www.unitylottery.co.uk or by phoning the Unity winners hotline on 0870 055 2291

The promoter of this Unity lottery is Caroline R Morrice, Woodholme House, Heckington Business Park, Heckington, Lincolnshire NG34 9JH

Registering authority: North Kesteven District Council Registration number: SL0229

HOW TO JOIN

the GAIN lottery

3 easy steps

Using this form:

1. Complete your personal details – so that **Unity** can contact you if you win.

2. Select the number of **Unity** lottery entries you wish to purchase per week and how often you wish to play.

3. Complete the direct debit instruction or enclose a cheque. Send your form to The Unity Lottery address below.

Freepost RLZR-GSYJ-KSZA
The Unity Lottery
BARROW-IN-FURNESS
LA14 2PE

unity

gain
Guillain-Barré & Associated Inflammatory Neuropathies

1. Your details (please print in block capitals)

Title:	First Name:
Surname:	
Address:	
Postcode:	
Tel:	Mobile:
D.O.B	If you would like to receive correspondence via email, please tick here ☐
Email:	

☐ If you do not wish your name to be publicised if you win, please tick here

2. Payment Frequency

How many entries would you like each week? ____ x

How often do you want to pay? (please tick payment frequency & write amount in box)

- ☐ Monthly / £4.34 Direct Debit only
- ☐ Every 13 wks / £13
- ☐ Every 26 wks / £26
- ☐ Every 52 wks / £52

x ____ =

Total Payable ____

3. Select your Payment method

Banks and Building Societies may not accept Direct Debit instructions for some types of accounts DD15

Please fill in the form and return to **Unity**
Freepost RLZR - GSYJ - KSZA, Barrow-in-Furness, LA14 2PE

Name and full postal address of your Bank or Building Society.

To. The Manager:	Bank/Building Society
Address:	
Postcode:	
Name(s) of Account Holder(s)	
Branch Sort Code:	
Bank/Building Society account number	

unity Instruction to your Bank or Building Society to pay by Direct Debit

DIRECT Debit

Service User Number: 4 2 1 1 0 2

Reference:

Instruction to your Bank or Building Society
Please pay **Unity** from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with **Unity** and, if so, details will be passed electronically to my Bank/Building Society.

Signature: ____

Date: ____

☐ **Payment by Cheque** ☐ I enclose a Cheque made payable to **Unity** (minimum payment £13)

4. Your consent to Play (I confirm I am over 16 and resident of GB)

Signature: ____ Date: ____

For office use only:
g4all05

☐ If you would prefer not to receive other forms of communication from your chosen society, please tick here.

Freepost RLZR-GSYJ-KSZA
The Unity Lottery
BARROW-IN-FURNESS
LA14 2PE

www.unitylottery.co.uk

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.

CIDP

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.

about gain

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.

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

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1800 806 152 (ROI)
Registered Charity 1154843 & SCO39900

NEWS from the office

As we pass the 1st birthday of GAIN we can report that we have seen an increase in people with CIDP and other associated inflammatory neuropathies contacting us for help and information. However, the flip side is that we are finding that people are happy to register and support us through a donation or by fundraising but are not interested in being a voting member of the charity. Projecting this forward shows a major risk to our charitable status as a member driven organisation. The Trustees and Management team are looking into and will raise it at the AGM.

The AGM will be held on 20 June 2015 in Peterborough. Members who wish to propose a motion should submit it in writing and either email it to secretary@gaincharity.org.uk or post it to Director GAIN, Woodholme House, Heckington Business Park, Station Road, Heckington Sleaford, NG34 9JH to arrive no later than 22 May 2015. Full details of the AGM including the agenda will be sent to voting members 2 weeks prior to the event. Details will also be posted on the website and social media.

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 12 June 2015. 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.

The next regional event will be held in Peterborough on 20 June 2015 at 11am, this is open to anyone and will include an opportunity to share stories and "Ask the Experts". More details will be available nearer the date.

The next issue of the magazine will be published in June 2015 and the deadline for submissions is 15 May 2015. Please forward all articles to Lesley Dimmick fundraising@gaincharity.org.uk

Meet the Medical Advisory Board (MAB)

1. Who are you?
Dr Rob Hadden FRCP PhD Consultant Neurologist & Honorary Senior Lecturer King's College Hospital

2. Where do you work?
I am consultant neurologist at King's College Hospital, London, and Maidstone Hospital, Kent. I run the regional service for people suffering all sorts of peripheral nerve disorders.

3. What is your role on the MAB?
MAB member

4. Do you have a special interest in GBS/CIDP or one of the variants?
I was part of international committees of experts that wrote guidelines for diagnosis and treatment of CIDP, paraproteinaemic demyelinating neuropathy, and vasculitic neuropathy. My earlier research looked at the differences between axonal and demyelinating GBS.

5. What inspired you to join the MAB?
I became interested in GBS doing research towards a PhD with Professor Richard Hughes at Guy's Hospital, London. I liked the idea of using my knowledge to inform and support sufferers more directly than just by publishing in academic journals.

6. What current global research excites you?
Clinical trials of new treatments, such as new drugs (eculizumab for GBS and fingolimod for CIDP), better ways of giving immunoglobulin (such as faster-infusing subcutaneous forms), and better forms of exercise and physiotherapy.

7. Finally do you see a time when GBS and CIDP are preventable?
In the next few decades I think we will get better at switching off these diseases but I am less optimistic about preventing them starting.

Report from our first Regional Event (South East)

In response to the survey undertaken after the last conference (and the subsequent cancelled one) the first regional event was held in the South East on 21 March 2015 at Shorne Village Hall in Kent. 1047 people were invited to attend and disappointingly, given the high number who wanted a less formal and cheaper option, only 40 registered to attend (less than 2%). As many of the attendees were joining one of our events for the first time we found that this was a successful gathering of those affected by the illnesses.

On arrival people grabbed a coffee and started chatting and sharing experiences. A brief outline of what was happening in the office and in the wider neurological field was given by Caroline.

Dr Rob Hadden, Consultant Neurologist at King's College Hospital, London, is on the GAIN medical advisory board and started by telling us all a little bit about various trials and studies which are taking place, beginning with HINT, the Home exercise in Inflammatory Neuropathy Trial, funded by GAIN and being conducted at King's College in London. The team are grateful for the financial support from GAIN and for putting people in touch who were interested in taking part. Out of the 55 people currently taking part, 35 became involved through the charity, with others being recruited through King's, the National Hospital for Neurology & Neurosurgery, and Birmingham. This research is due to complete at the end of 2015. The report once published will be available through GAIN. He said that there is quite a lot of medical research looking at IVIg, etc, but much less looking at later stages of recovery.

Rob then went on to talk about how immunoglobulin treatment can be given subcutaneously (known as subcut or SCIg). Many people with CIDP have ongoing IVIg treatment, perhaps once every 3 to 8 weeks. This involves travelling to hospital and taking time off work for a stay in hospital which is not ideal. It is now possible to receive immunoglobulin in a more convenient way at home. Subcut requires visits to hospital for initial training and also for periodic check-ups but is then very easy to give to yourself at home, taking about two hours once a week (may be more or less time depending on the brand and pump). It generally gives fewer side effects than IVIG and it's good for people with very small veins. If a person has problems with their hands, their partner or spouse can be trained to assist.

It isn't perfect, and some people get lumps and bumps under their skin, and most need several needles at once depending on dosage, but the technique is improving. Of course, some people prefer attending hospital, but offering subcut provides a choice for those who would rather not if they don't have to. The satisfaction rate was very high from a recent small clinical trial, with 8 out of 8 people wanting to continue with subcut afterwards. It was however a self-selected trial and those taking part were all on fairly low doses, so it might not suit everyone. A new type of subcut immunoglobulin has been developed, which contains an added substance to allow the liquid to spread out easily under the skin, allowing 10 times more to be administered through a single needle. This means that a higher dose can be given more quickly. However this type isn't yet licensed for the treatment of CIDP.

Subcut is currently available through several centres around the country including King's, Queen Square and Oxford, but if it isn't available where you live, you may be able to be referred elsewhere to be trained and then carry on at home.

Rob then went on to talk about developments in prediction of outcomes following a diagnosis of GBS, i.e. would this person be expected to do badly or to recover well 12 months on. The

strongest predictor of a worse outcome is worse overall severity; older people recover less well on average, as do people who had diarrhoea just before GBS started. Other factors such as a positive attitude and overall level of fitness prior to onset have not been measured.

Recently, however, people have focussed on other outcome measures apart from the ability to walk without a stick. The R-ODS score (Rasch-built Overall Disability Scale) contains 24 questions centred around everyday activities, for example asking if you can run, do the dishes, go up and down stairs, turn a key in a lock, etc, with responses ranging from 'not at all', 'with some difficulty' or 'easily'. This questionnaire is then scored out of a possible total of 48 to establish current degree of ability and also to detect change and improvements over time throughout a course of treatment (for example before and after IVIg).

We were then shown a piece of equipment called a Martin vigorimeter – a rubber bulb attached to a gauge measuring the strength of grip in each hand. It is a simple, easy to use and reliable measurement tool that can measure small changes in strength that may not be noticed otherwise. In response to a question on fluctuating grip Rob stated that there are many other factors that affect grip, including health, fatigue, stress, etc, and if they borrowed a Martin vigorimeter to take home, they could measure their grip at several different stages throughout the day / week and map the results on a graph, and identify emerging patterns in the average strength.

Rob then touched on the Cochrane Reviews which give an overview of all the published research trials for a particular disease or treatment. One of these was a trial in China which had looked at the possible benefits of a herbal remedy made from a plant called Tripterygium wilfordii, also known as the 'Thunder God Vine'. During the trial, 22 GBS patients were given the remedy, and another 21 were given steroids. After 2 months, there was slightly greater improvement in the group treated with the herbal remedy, however, this trial was small and considered unreliable so this treatment is not likely to come into general use without further research.

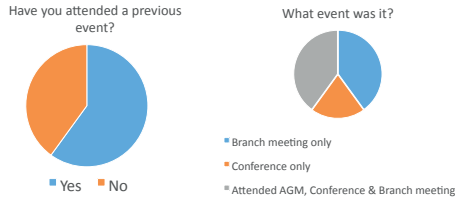
In 2012 a trial in CIDP, involving 45 people, looked at IVIg versus treatment with steroids (iv methylprednisolone). 88% of people receiving IVIg showed improvement, but 38% of those who improved got worse once treatment stopped. On the other hand, of those receiving steroids, 48 % improved, and after treatment stopped none of those who had improved worsened in the next six months. This might indicate that if symptoms aren't too bad, then it is worth trying steroids as this might result in longer lasting benefits (and is cheaper), only switching to IVIg if there is no real improvement after 2-3 months. However, if symptoms are very severe, it might be worth going straight to IVIg.

IGOS is an international study of outcomes led from the Netherlands, and is the largest study of GBS done to date. The aim is to recruit 1,000 people with GBS in a non-treatment, monitoring-only study to assess factors predicting outcomes, with frequent blood tests to identify molecules that may be important in the disease or recovery.

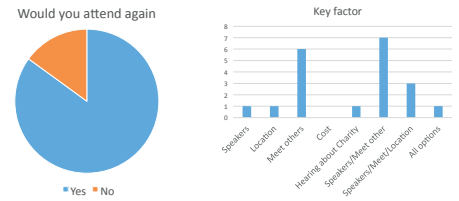
South East Regional Event

FEEDBACK

Have you attended one of our events before?



Reasons for attending



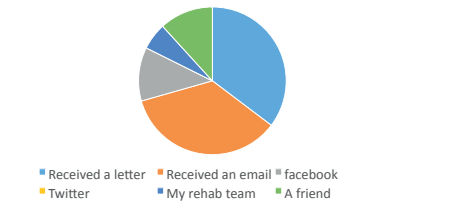
What would interest you at future events?

- More about the problems of GBS etc
- Information about support available for spouse and family members
- Updates on research being undertaken globally
- Patient speakers
- More speakers
- Meeting people with similar symptoms
- Explain the medication used for treatment & any major side effects

Comments

- Very enjoyable and worthwhile event
- Great day, very informative
- Why isn't information about the charity handed out by hospitals
- Would like to have more localised groups
- Super event would definitely attend again
- So lovely to talk to others and hear their experiences
- Good and important that the office team were able to attend
- Very interesting day
- Made to feel involved and welcome
- Journey very long would attend again if nearer to home
- Thank you!

How did you hear about the event



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Ask the Expert

(Question and Answer Session from the Regional Event)

If you have GBS, what are the chances of getting another autoimmune disorder?	There is probably a small increased risk in that a few people with GBS or CIDP may go on to develop a further autoimmune disorder. These disorders are caused by the failure of immune tolerance. The immune system is designed to attack foreign bodies, but it sometimes gets confused and the system breaks down. If you have one, you are slightly more likely to get another, but if you get them together, some treatments can treat both at once.
Are people living closer to the equator less likely to develop autoimmune diseases?	This is true for multiple sclerosis (MS) but not proven for GBS or CIDP. Some people think this may be down to genetic differences. It may be more likely related to vitamin D. Therefore the more sunshine you get, the better it is for the immune system. This is not proven and is based on assumption, but a lot of MS doctors recommend taking a vitamin D supplement in winter. Perhaps CIDP sufferers may like to try this. In the UK, we tend to have lower than normal levels of vitamin D and I'm sure we'll hear more about ongoing research in the future.
Can you have a booster of IVIg when symptoms are bad?	For GBS, it is recommended that a person has a course of IVIg in the early stages. About 10% of people with GBS have an early relapse ('treatment-related fluctuation') after about a month, because the benefit may wear off before recovery is properly established therefore IVIG may be repeated. About 3% of people with GBS might go on to have a recurrence years later, in which case IVIg would again be recommended. It would usually be recognised and therefore diagnosed more easily the second time around. Sometimes what appears to be GBS is really the beginning of CIDP (this is called acute-onset CIDP). This would call for the standard CIDP treatment of either IVIg or steroids. There could be other factors causing people to feel worse which are not related to inflammation of the peripheral nerves, such as depression, stress, lack of fitness or other health issues. It could be that you just don't have the reserve of mental energy you need to deal with these other factors that decompensate you, but this wouldn't be helped by having another course of IVIg.
I've had Miller Fisher several times and have now been told it's Bickerstaff encephalitis. Is there a difference between Miller Fisher and Bickerstaff?	Miller Fisher commonly causes unsteadiness and weakness of the face and eyes. Bickerstaff's Brainstem Encephalitis is Miller Fisher plus inflammation of the central nervous system affecting the brainstem (with increased reflexes rather than reduced). Recovery may be slower and not so good. It is possible to get Miller Fisher more than once. Overall, the recurrence rate for GBS and Miller Fisher is 1-6%. Miller Fisher seems slightly more likely than GBS to come back again, so it could be closer to 5-6% for Miller Fisher and 2-3% for GBS. There was a study of people with apparent GBS which was subsequently diagnosed as CIDP. This was more likely in people with a lot of sensory loss, and less likely in people with constipation, weakness of the face or needing intensive care.
I had Miller Fisher 11 years ago and made a complete recovery. Over the last 9 months, I've noticed a loss of sensation in my feet. Is it coming back?	If you've been having these symptoms for 9 months, it isn't a relapse and is more likely to be unconnected, possibly another peripheral neuropathy linked to diabetes or something else. It could be a thyroid condition, vitamin B12 deficiency or a symptom of diabetes. You should be checked by your GP for other forms of peripheral nerve disease. It could also be decompensation due to stress or tiredness or could be a slipped disc or something else entirely. Talk to your GP.

Can osteoporosis cause these symptoms?	Not commonly. Get it checked out by your GP.
Does smoking and / or drinking affect treatment and is it bad if you have or have had GBS / CIDP?	Heavy smoking or drinking can cause problems with your immune system as well as other parts of your body. Look at the whole person and consider your heart, lungs, liver, etc. Damaging these will not help. Stop smoking and keep to recommended safe levels for alcohol intake.
I developed GBS 5 years ago following vaccinations for tetanus, hep A and typhoid. I'm getting lots of infections now and was wondering if this disruption to my immune system is related to GBS?	Can't give a definitive answer. Sometimes GBS can be provoked by a vaccine, other medication or trauma, but most GBS is not caused by any of these. If you developed GBS 2-6 weeks following a vaccine, it might have been the trigger, so it is best to avoid the same vaccine in future. The immune system is more active immediately following GBS. It is extremely rare for a GBS or CIDP sufferer to have an adverse reaction to a vaccine. Unfortunately there is no hard and fast rule; more research is needed.
Question about a lady in her 60s who had GBS 18 months ago. Now in care home, having had a partial recovery in arms but not in legs. Could things still improve after this long?	Improvements can still be seen up to 3 years on. In the meantime, assistive technologies such as an electric wheelchair, iPad or computer etc can help. Unfortunately these gadgets tend to be expensive and not readily available on the NHS. The Oxford Centre for Enablement has expertise in assistive technologies. Ongoing physiotherapy may be beneficial.
Do I still have GBS or did I have it?	You still have the scarring or after-effects. You have had GBS, and you still have ongoing residual effects.
I have a lot of back pain 12 months on. Is this common?	GBS can cause pain even before the weakness starts. The pain can continue sometimes for months and months. After about 12 months, most GBS related pain ceases, but pain may then be caused through bad posture or lack of mobility caused by the GBS. It may also be unrelated as back pain is itself very common. Try different forms of gentle exercise to see if this relieves the pain.

We hope to continue having an 'ask the experts' section in future issues of *gain4all* so if you have a question for our Medical Advisory Board, please email the office: office@gaincharity.org.uk or alternatively phone: 01529 469910. We will try to answer as many questions as we can.

fundraising reports

Valentine's Dinner

Ian and Anne Bennett held their 2015 Annual Valentine's Dinner on Saturday 14 February, "we had a super night with lots of local support and so much help from people including those who were unable to come" said Anne.

Breaking all previous records they raised £1,612.25; an amazing amount which will go towards the GAIN 24hour helpline and personal grant fund.

Ian and Anne would like to thank everyone for their continued support of the Charity; without the generosity, help and support of all their sponsors, family and friends, the event would not have been possible.

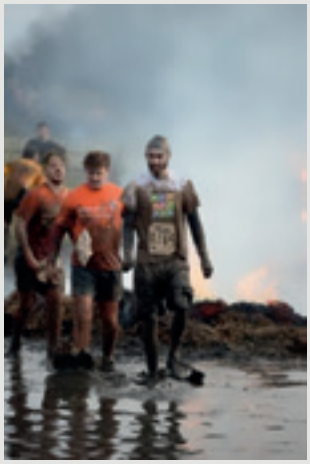
Masonic Lodge makes kind donations

Worshipful Master Geoffrey Whittle DFM, Daedalus Lodge, Sleaford presenting cheques to Kevin Roberts (Sailability) and Lesley Dimmick (GAIN).

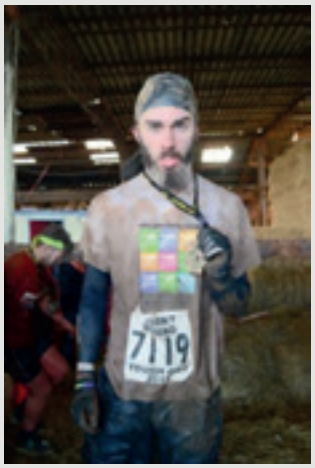
TOUGH GUY

I signed up for the Tough Guy to prove to myself that I could do anything I wanted to, but having come out of it the other side and raised money for GAIN, I realise that my running the race can do much more than that. It's proof to everyone that is diagnosed with GBS that anything is possible.

The race was brutally tough, with hill climbs, freezing cold lakes, electric wires, fire hazards, and 30ft high climbing frames to name a few obstacles. I met a wall when I was up on one of these frames covered in ice cold mud with a bitter wind cutting to my core. My legs were cramping, I couldn't feel my hands and I didn't know if I could take another step. But I pushed through, and from that point I didn't look back – failure wasn't an option. I was stopped by four paramedics telling me I had hypothermia and needed to quit the race, but my mental strength carried me all the way to the end and I completed what claims to be the toughest one day assault course in the world.



I think this serves as a really good metaphor for anyone with GBS. It's a horrible disease and at times you don't think you can continue, but for everyone out there that is struggling I urge you to keep going. Your mental strength can overcome your physical weakness, and no matter how many people tell you that you can't do things, you can. Keep yourself going and set yourself targets to meet, and before you know it you'll be at the finish line.



GBS changes your life forever, but if you use this change in a positive way you can achieve great things.

Jake Sharpe

Letter to the editor

Dear gain,

Hallucinations that won't go away...

Reading Andie Phillips' article "The stick is bigger than me", Winter 2014 edition of gain4all, brought back memories of my experiences during six months spent in hospital suffering from GBS.

I was struck down with GBS in June 2009 and after over five years I still have very strong memories of the hallucinations I suffered during the time I spent in ICU and which I cannot forget. Having said this I just can't remember any aspects of the medical treatment I received.

In my mind I witnessed families living on the ceiling of the ward to serpents coiling round the light fittings above my bed to my visitors apparently watching me from around a duck pond with railings (maybe the rails of my bed!). This all made for a very bizarre and disturbing experience which to this day, I still believe really happened.

Other hallucinations included my being wheeled into a room full of children with a castle like fireplace and being left in my night dress (I was never out of a hospital gown) to watch children skating on an ice rink in the hospital and a doctor's grandfather looking like Willie Wonka organising the proceedings. I was so sure that this was really happening that it took my family a long time to reassure me when I was able to tell them after being taken off the ventilator what I had experienced.

I thought this might be of interest to the magazine.

Best wishes
Jennie McNeill

It must be **man flu!**

In January 2013 I felt a little bit stiff, the result of the man-flu I was very obviously dying from.

My 'stiffness' was down to Guillain-Barré syndrome although we didn't know that at the time, and neither (it transpired) did the doctors on my first visit to hospital, as they sent me back home.

Over the weekend my stiffness became more pronounced, and I was unable to move from the sofa. On the Monday morning my wife (7 months pregnant) and a friend carried me to the car and took me to the local doctors' surgery, who thought I'd been involved in a car crash after seeing my inability to stand, walk or move my arms. After talking to me he declared that I "must have trapped a nerve".

Monday night and my friend John phoned an ambulance as I was unable to see, hear or respond to simple questions, couldn't move, and was struggling to keep my eyes open. I didn't see the house again for a few weeks.

Several lumbar punctures, an MRI scan, a CT scan and about a million blood/urine/stool tests later and (I don't know this as I have no idea where I was) I'm lying on a bed in the ICU, in a corner, with 'unknown condition' written on my notes.

On the Thursday a consultant neurologist returned from his holidays, took one look and declared "GBS". A huge 'thank you' to Dr Stefan.

Onto the treatment: IVIg, replacing my white blood cells with synthetic ones. I have no idea about any of the events surrounding this, but it must have done something, because over the next few days I regained some level of consciousness, and can actually remember some of the events of the next few days.

I definitely remember my hot water/urine bottle being red, which prompted the nursing staff to call a doctor, who took one look at my yellow complexion, the bag full of urine/blood and ordering tests to check on my liver function. The results? Liver 0: IVIg 1

The next few days are a blur of being bathed by nurses and my very pregnant wife, being pumped full of suppositories and laxatives, being craned on and off the toilet, vomiting, crying and an absolutely desperate feeling of uselessness as I was supposed to be looking after my wife who should have been taking it easy.

By Valentine's Day I was eating solid food (I can definitely recommend those nutrient-rich drinks as the most disgusting thing ever invented), and the wonderful staff allowed Michelle to come in and feed me, although absolutely no alcohol was consumed by either of us as it is against hospital policy. It was the best thing I'd ever eaten (but not drank, obviously as there was no alcohol involved), and I think this single act made me realise that I needed to kick GBS into touch and get back to the business of being a proper husband.

And so began the physio and occupational therapy. Who would have thought that sitting up would be so tiring? By February 21st I was finally declared to be not ill anymore and was moved to Chatsworth Rehabilitation Centre to learn to walk again. How can you forget something

you've been doing for more than 40 years? Apparently you can, because I did. My brain wasn't sending the signals to my legs, or it was getting blocked en-route. Cue the electrical tests. Stick a needle in the top of your leg, another in your foot, attach cables and fire about 27 bzillion volts through the unsuspecting victim/patient. There was no doubt that feeling had returned to my body. Whatever my personal torture was it seems that my wiring was still slightly off and needed to be worked on with my occupational therapist.

Physio sessions focused on improving (actually introducing) core strength before building stamina, balance and mobility, and I have to say that it was extremely hard, tiring and emotional. It was made slightly easier by the fact that one of the team looked like Cameron Diaz and I was always first in the queue for treatment.

Eventually my arms became strong enough to propel my own wheelchair and I would sneak into the PT room, strap myself into the powered exercise cycle and rack up a few miles whilst entertaining the unit with my X-Factoresque accompaniment to my iPod. They loved me so much that I would open my eyes and there'd be a crowd around me shaking their heads in disbelief that such a sound could come out of a middle-aged man with no vocal training whatsoever (that's what I believe and I'm sticking to my version).

At some time during my stay in rehab I developed Bell's Palsy, from which I have made a full recovery, apart from some optical focussing issues (although that could arguably be age-related), don't know where it came from, what caused it, or why it went, but I swear I was the spit of Johnny Depp whilst I was wearing the eye patch.

On 26th February I received a phone call to say that my long-suffering, beautiful, dutiful wife had gone into labour, and after much pleading and many promises that I would return immediately I was allowed to return to hospital to see my son being born. The delivery suite was furnished with another bed for me, and by a surprising quirk of fate the midwife that delivered my gorgeous boy was the daughter of one of the nurses that had authorised my being there for the birth.

I spent another month in rehab before being allowed home to continue as an out-patient, and with the intense sessions and the exercises that I was given to perform at home I was walking, unaided by August.

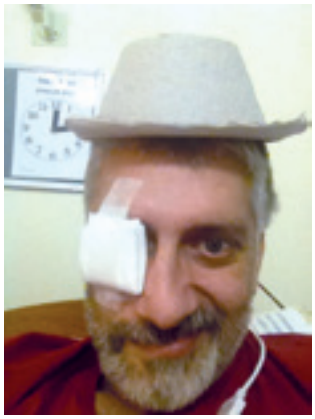
I was eventually declared fit for work again by January 2014 and, although my job is not particularly arduous, I was surprised by just how physically exhausting walking around and talking to people is. Almost a year later and I still have to pace myself, but I climb 200 steps 5 times a day, and feel ready for a challenge now, hence my decision to run 10K and try to raise awareness (and money) for GAIN.

In January 2014 I also discovered that most of my body had returned to its former, magnificent glory, as Shell declared that she was pregnant, and in September 2014

she gave birth to the hairiest, prettiest little girl to complement our stunningly handsome and talented 18 month-old son.

Huge (and frankly inadequate) thanks are given to everyone who helped me get through it.

by Adam Scorcese



Inside Health

Programme Transcript – featuring GAIN volunteer Sue Ide-Smith and secretary of our Medical Advisory Board, Jane Pritchard

Presenter: Mark Porter
Producer: Geraldine Fitzgerald

And we investigate Guillian-Barré syndrome – a rare but fascinating cause of paralysis.

You are listening to Inside Health, I am Dr Mark Porter, and this is the part of the programme where you set the agenda.

We have a tweet from a listener concerned about a friend who has been admitted to hospital with a rare type of paralysis called Guillain Barré syndrome. Could Inside Health please explain what it is, and how it is treated? Questions I put to consultant neurologist Jane Pritchard. But first someone who knows all too well what your friend is going through.

Ide-Smith
My name is Sue Ide-Smith and I am a Guillain-Barré survivor. Yes I used to work in advertising in a media advertising agency and I was a managing partner, and so I ran quite a big team working on major corporate clients and yes, so I was doing that when I got taken ill. And so basically I had no choice in the matter I couldn't carry on with work when I got ill because it was a very sudden onset, the illness, and it basically took me from – I had flu, but it took me from having flu and being off work with flu to being in intensive care within 48 hours.

Pritchard
Guillain-Barré syndrome is named after two French neurologists who described the condition in 1916 in two First World War soldiers who were taken ill at the front when they developed weakness.

Porter
You'd have thought those French neurologists would have had better things to do during the First World War, it must have been a pretty awful time.

Pritchard
Yes it was just after the Battle of the Somme and they found these soldiers who had developed weakness and they took the time to do a lumbar puncture on them to demonstrate that the protein was high and yet there weren't cells which meant it wasn't polio, it wasn't other infectious conditions. And to do basically research, electrical studies, to confirm the problem was in the nerves after the spinal cord. It's astonishing.

Porter
How does a typical case present?

Pritchard
Often at the beginning people develop a little bit of tingling, perhaps in the hands and

feet, and then gradually they develop weakness and that weakness can progress very quickly in some cases, some people can barely move within 48 hours, other people the weakness progresses over a number of weeks, and they can become paralysed in their arms and legs, they can have difficulty with breathing, difficulty with swallowing and even difficulty with moving their eyes in the most extreme case.

Porter
As a medical student I was taught this was an ascending paralysis, so it starts, if you like, at the feet and works its way up, is that true?

Pritchard
That's the classical presentation but something that sometimes catches us out is that often there can be weakness around the movement of the tops of the legs.

Porter
And what's actually happening to the nerves?

Pritchard
Let's be clear, it's not the central part of the nervous system that's the problem here, the brain and the spinal cord are fine, the nerves after they've left the spinal cord are not conducting the signals properly. And what's happening at the microscopic level is that we think the immune system is attacking the nerves, so it's a combination of block of signal and damage to the nerve.

Porter
And so it's an example of what we would call an autoimmune disorder, where the immune system is attacking…

Pritchard
That's right.

Porter
…instead of attacking an invader it's attacking our own body, what triggers it?

Pritchard
Well we know from epidemiology – that's the study of populations – that people have reported an increased incidence of infections often before Guillain-Barré syndrome begins. So two-thirds of patients describe an infection, perhaps in up to four weeks before the onset of their neurological symptoms, may be flu like illness, may be viral illness, that they didn't really even think much of, they may not have even needed to take time off work and then in the weeks following they develop Guillain-Barré syndrome.

Porter
How do you manage it?

Pritchard
When the patient first presents the first thing is to recognise that that's the problem, so your average GP might only encounter one case in their whole lifetime.

Porter
Well I've never seen a case.

Pritchard
So that's the first thing. Similarly getting through casualty, a lot of patients get turned away from casualty the first time that they present because they're just describing tingling and nobody can detect any weakness. Once it's been diagnosed or suspected the patient would be admitted and carefully monitored because of the problems with the breathing and because of the problems that can develop with heart rhythm. And then to try to stop the immune process from going on there are two main treatments – the first one that was described was called plasma exchange but it's been shown that another treatment, called immunoglobulin, is equally effective and immunoglobulin is taken from blood donors, the immunoglobulin factor is pulled together and then administered to the patient over a course of five days. And that is much easier to give than the plasma exchange that used to be the first line treatment, so nowadays immunoglobulin would be first line treatment but they both work equally well.

Ide-Smith
When I came to in ICU my family told me that I had been totally paralysed, I was still 95% paralysed. When I was totally paralysed I had no expression in my face and I couldn't move my mouth, so I couldn't even mouth words at them. And I couldn't speak because I had a tracheotomy.

So it's an incredibly – and your brain is 100% operational. So you are trapped inside your body. It is like a temporary version of locked in syndrome and it's absolutely terrifying.

I had been in neuro-ICU for about three weeks when I realised where I was. The first time when I knew I was getting better was when I realised I fancied my physio – that was a good thing. And gradually things changed, like my fingers started to move or my toes started to move but it was excruciatingly painful. And then I was in ICU for two months and then I got moved to a ward. The first time I stood up and I thought I'd been standing for about two minutes and I was sweating buckets, it was so much work, it was so hard. Then the physio said – that was 20 seconds, that's fantastic. And I was like – Only 20 seconds! That's so annoying.

Porter
And what's the outlook, somebody's come in, they are two weeks into their illness and they are under your care and they say to you – doctor am I going to be alright? What do you say to them?

Pritchard
It depends on quite a lot of factors. So probably about 80% make a good recovery, 15-20% are left with significant disability, so by that significant weakness, sometimes pain, they might need a wheelchair, they might need walking sticks. If you look in the world population it still has a death rate of 4%...

Porter
One in 25.

Pritchard
Which is quite significant.

Porter
So the paralysis has ascended and they can't literally breathe for themselves so they're on a machine and that's associated with lots of other issues.

Pritchard
Yeah, complications of that. But even those who make a good recovery a significant number, probably at least 20%, are troubled by significant fatigue, ongoing tingling and perhaps are not back to full functioning as they were before they were ill.

Ide-Smith
Effectively it took me 18 months to get to a reasonable standard of living, I wasn't working, I couldn't have worked, I was resting every afternoon but I had a reasonable quality of life. We're now nine and a half years on, I'm a lot better, I can run, I can walk, I've got my dexterity back, I'm lucky some people don't get that, so I am able to make jewellery, which is what I do now – I make jewellery and I sell lovely organic natural healthcare as well, so I have work that fits in around my fatigue, rather than trying to fit my fatigue around my work. I still have to rest every day but if that's one of my only side effects then I don't really think that's a difficult thing to deal with considering I could have been left in a wheelchair or I might not have made it at all.

It has totally changed my life but now in a way I can help other people with these illnesses, I can do more voluntary work which I really enjoy. I think it's changed my life for the better because the most important thing that came out of it for me was realising how important my family and my friends were and that I certainly would not have wanted to carry on the way I was carrying on because I didn't have enough time to spend with my family and my friends at that stage and now I do and I make that a priority. And so I'm very grateful for that.

Porter
Sue Ide-Smith. And thanks to neurologist Jane Pritchard from Charing Cross Hospital in London. You will find some useful links of GBS on our website, where you will also find details of how to contact us.

Victoria Left to right, Robert, Alan, Graham and me at rear

And The Band Played On

Aged 61 and following a life of being in rock bands, a solo performer, success in local and regional politics, running a business and a happy second marriage, this is a fascinating insight into the madness, mayhem, joy and wonder of my musical career which almost stalled because of GBS...

How it all began

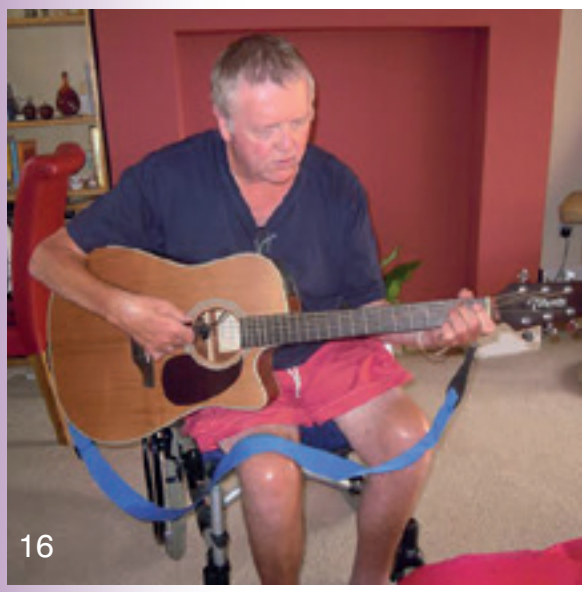
I had long harboured a desire to play guitar and as a child of about five or six, I would watch Lonnie Donegan and Tommy Steele on our old black and white television set. I used to pick up a plastic toy tennis racquet and pretend to strum along. The sense of wanting to play stayed with me and when I was fourteen, my mother bought me a cheap guitar whilst we were on a family holiday in Italy.

I did what most young aspiring guitarists did in those days, I bought the late, great Bert Weedon's guitar book, 'Play In A Day' and the book '500 Chord Shapes' which was all I needed. I had a head overflowing with songs I wanted to play and knowing how they went, I used the chords in those two great books to begin actually playing. That's the only teaching I've ever had apart from observing other players I've met down the years.

School friend Robert Gittins (a pianist) and I both shared a liking for contemporary pop and rock

Shildon Civic Hall 2011

Darwen 2013



Home, August 2004 attempting to play again

music so we got together and started by learning a few songs from The Monkees (a primetime American TV show about a zany group of west coast pop musicians, which was all the rage at the time). We were soon joined by friend and drummer Alan Rowley. After leaving school and getting jobs, we almost drifted apart but Alan worked at a local hospital so in exchange for use of their dining hall for practice, we put on shows for the staff and patients.

Alan's younger brother, Graham, also a guitarist, joined us for the hospital gigs and I gave up playing six string guitar and begun playing electric bass. Whilst these monthly shows at the hospital were fine, we rather fancied spreading our wings – so I rang a local music agent Eric Tarn, and asked his advice. He first of all asked what our name was and even though we didn't have one, he simply invited me to bring the band, or group as they were known in those days, along to audition the following week. We got the shock of all time when, just a couple of days later, Eric got back in touch saying, "Don't bother with the audition. Call yourselves Victoria and get over to Washington Celtic Club on Saturday. I've booked you to play there." Nerves and excitement in equal measure gripped the four of us. We persuaded another friend, Mick Cooper, to be our roadie, my brother Andy was asked to wear a suit and pretend to be our manager, we hired a van and off we went. It wasn't the best opening performance but we were on our way from that point onwards.

By the autumn of 1974, we had a 'proper' manager and we were playing every weekend and sometimes midweek, too. It was one of the best times of my life back then but things were becoming crazy. Four young men, replete with entourage, attitude and ego, travelling up and down and across the roads of North East England, having a whale of a time with no signs of slowing down, was not always a pretty sight. We never caused trouble, but you wouldn't have been too keen on introducing us to your mum or girlfriend! Away from the band, I found myself unemployed and on the dole so applied to become a Christmas casual at the local delivery office and ended up being offered a full time position. Life on the road and getting up at 5am to start work soon became incompatible so I decided to leave Victoria – a decision that I regret to this day. Anyway, the other three got a new bass player and went on their way without me. Sadly, Robert and Alan are now no longer with us and Graham lives near Worthing and still performs occasionally. By 1976 I had married and was divorced in 1982. This wasn't the happiest time of my life but now and then I'd join some local troubadour or two on stage in a non-professional capacity. I also formed one or two rock bands but none were ever as good as Victoria. When I met Janet, my now wife, my life changed again and I stopped performing all together when we became a family. Still working at Royal Mail and involved in trade unions I swapped music for a life in politics, becoming a county councillor and parliamentary panellist for the Communication Workers Union. I was settled, a husband with a loving wife and a father of two sons.

Eventually I returned to live performing

Around 2002, I was invited along to a local Folk Club and although I had never had much interest in folk music, I played a few songs and met some of the nicest people you could ever

Bishop Auckland 2009

wish to meet around the folk club circuit. From there I travelled extensively as a solo performer and got to know performers and venue owners throughout the North East and North Yorkshire with occasional forays into Lancashire and Cumbria. I took early retirement from Royal Mail and set up my own photography business. But more than that, I was back, performing my songs and truly happy.

In 2008 I was booked to play a St.Patrick's Day gig in Newton Aycliffe and I invited a guitarist friend of the time, Gary Grainger, to accompany me. Gary agreed as long as his friend, David Pratt could come along, too. David, the finest percussionist I have ever played with, learned our songs just half an hour before the three of us went on stage. It was perfect. So much so that the three of us became Trí and took to the road playing a mix of Irish stuff and our own songs. Gary left in 2010, citing personal problems and David and I brought in Ken Robinson and Steve Eliffe to form a new Folk, Rock, Blues band called Dead Cat Bounce which later morphed into today's outfit known as Man With The Stick. Steve left last year to go solo and our current line up includes David, Ken and myself along with newly joined guitarist, Geoff Pickering and fiddle player, Mags Forward.

And then I was struck down with GBS

My GBS journey began in October 2013 and I don't need to tell you just how bad that was but being a glass half full person and the thought that one day I might walk out of hospital, kept me focussed. There were times, I must admit, when staying focussed was a challenge.

I had been told that GBS was recoverable but there could be some residual and long lasting debilitation of either hands or feet. As you would imagine, the guitarist in me hoped that my hands would be spared. No such luck. Today I use a wheelchair, crutches, walking sticks and a walking frame as required. I can move my legs freely although I can only walk unaided for a few yards. I can move my arms freely, too, but I have no feeling in the little and ring fingers of both hands. Additionally, my right hand is somewhat 'clawed' in shape and the wrist extension is very weak.

So! End of musical career? Not on your life! I now just sing in *Man With The Stick*. With the aid of a perching stool I can get myself reasonably upright without falling over and with four excellent musicians around me the band is live once more. Do I miss playing guitar? You bet I do. But I am confident that one day I shall be able to do so once again. Right now, I am happy to be able to continue performing. My voice is strong and the joke is that I am now the 'man with two sticks'.

Phil Graham
Man With The Stick

www.facebook.com/MWTSmusic
www.bandmix.co.uk/phil85724

CIDP the birth of my princess

My journey began in April 2013. I was a stay at home mummy with my two beautiful boys, and William my partner. I was healthy at thirty five weeks pregnant, excitedly looking forward to the birth of our daughter who we had already named Kelsey-Mae Patricia. I started with unbearable back pain, after a while as it wasn't getting any easier I went to the hospital thinking I had gone into early labour, they admitted me for an overnight stay as my blood pressure was low, by morning I was sent home as the baby didn't seem ready to be born. As the day progressed my tongue felt all tingly like I had burnt it on a hot cup of tea, then my hands and feet felt tingly and I became totally exhausted, I tried to get some sleep and rest but the back pain was so bad I had to visit my GP, it was all put down to the pregnancy and I was advised to rest, which was nearly impossible. Over the next twenty four hours the pain came and went so I did manage to fall asleep, but on awaking I realized something was seriously wrong as my face had dropped on the right side, I shouted for my mum who had stayed to help William with the children. We rang 111 and an ambulance arrived and took me to A & E, then I was transferred to the medical assessment ward where I was now diagnosed with Bells Palsy; they gave me steroids to take and I was discharged. I went home but I couldn't stop being sick and my balance was affected. I managed to sleep for a while but over the next twenty four hours I became worse, I woke up to find both sides of my face had dropped and I had lost the use of my right leg and kept dropping to the floor which was very worrying being so heavily pregnant. I knew there was something very seriously wrong but no-one was listening to me.

> "the first thing I could think of was my children, I need to go home to look after them

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

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

Another few weeks later and I started to improve, I felt movement coming back in my hands and fingers; I started to use the speaking valve and trained my breathing ready for the tracheotomy to be removed. I remember the first day I used a hoist; the pain was unbearable but couldn't tell the staff, my legs felt like they were being pulled off my body. When I sat in the chair it felt like thousands of pins stabbing my entire body, and at this stage I couldn't hold my head up. Eventually I was moved to the ward still with the tracheotomy in, and I could sit in the chair more comfortably. Most importantly my children could visit me every day. I was now determined to beat this illness and go home to where I belonged with William and my children. I started to use a standing hoist with the physiotherapist and although the pain was still severe it was worth it as it was nearing the time to be allowed home for short periods. August arrived and I was allowed home for the first time, it is a day I will never forget, I realized how much I had missed being away from the children so long, the boys had grown and Kelsey-Mae had started to smile, I felt it so unfair. By the end of August it was approved that I could go home until rehab was organised. I was still bed bound or chair bound but I was home with the children, William and my family. It was October 2013 when I was transferred to rehabilitation to begin the hardest phase of my recovery. I did start to improve more quickly from this point, and in February after four months in rehab I was out of my wheelchair and walking with a frame. March came and I had a setback with the symptoms returning, so had to return to The Royal Preston Neurological Hospital for a course of IVIg. Eventually I was diagnosed with CIDP. April 2014 and going home at last walking with a stick, home to my family.

I have fortnightly treatments of IVIg and steroids. Sometimes I still have neuro pain in my feet and I ache, fatigue is persistent and some days I really struggle, but my life is going well at the moment. I am grateful for the support I had and still have. William who stood by my side all the way. I couldn't have got through it without my family. I love my princess Kelsey-Mae who is mummy's little girl, my boys Mckauly-Dean and Kayden. I try my best now to do activities with my children and be the best mummy I can be, we have lots of fun. I am grateful for the life I have and the people in it. If it wasn't for Guillain-Barré syndrome I wouldn't have met some of the most amazing people, the staff at The Royal Preston Hospital, staff at Rakehead Rehabilitation unit, and the lovely people of the Lancashire and Cumbria Association of GAIN who have been a great support.

Kayla Bufton

Listening books
Speaking Volumes

Listening Books is a charity that provides an audiobook library service to children and adults who struggle to read or hold a book due to an illness, disability, learning difficulty or mental health difficulty. Audiobooks not only provide a link to the wonderful world of literature but can be a relief from pain or anxiety, lifting members out of what are often challenging circumstances. The service caters for children and adults with a wide variety of impairments, offering a huge library of over 7,000 titles in a wide selection of genres, as well as a large educational library for those still at school.

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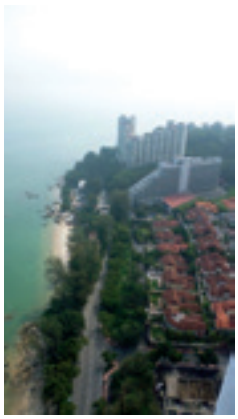
Mastering the Art of Life in Malaysia



Malcolm Hanney faced some unexpected challenges when he made a new life for himself in Malaysia.

Three years ago, while my son Steven and I were visiting Malaysia – he was doing a few weeks' work experience with the YTL Group in KL – we decided to take a weekend trip to Penang. On the way, we stopped off overnight in Batu Gajah, where before WWII his great grandfather had managed the Kinta Kellas tin mine. The tin mine, which had still been operating in 1981 when I made my first visit to Malaysia, is now the Clearwater Sanctuary Golf Resort.

While Steven and I were in Penang, I began to think that maybe this was the place to spend my twilight years – plenty to do, warm weather, a beautiful island, friendly people, great food, low cost of living and low tax, and a good base for travel in Malaysia, Asia and beyond. I also wouldn't have to change any of the plugs on the electrical appliances! A year later, I had decided to apply for an MM2H visa and started to plan my new life in Malaysia.

In 1993, I had decided to retire early from my career in international finance. However, I had remained very busy and involved in a wide range of public and charitable activities in the UK. I knew that I wasn't quite ready for a 24/7 retirement life – so what to do? It was then I had the crazy idea that as I was approaching 60 I needed a new challenge.

After 38 gap years, what could be better than studying for a Masters degree in Southeast Asian Studies at the University of Malaya in KL? I thought that would work out really well while my apartment at Batu Ferringhi was being completed. So it was that in early September 2012 I arrived with my satchel at the University of Malaya to meet my fellow students, all but one less than half my age.

My fellow students, a mix of Asian nationalities and two young German women, were wonderful from the start, making me feel very welcome and a full member of their group. I was later to be taken to bars, comedy clubs and other places that I am sure that they would never take their parents.

The first few weeks were pretty difficult. A course on Research Methods from 9 am to 6 pm every day (plus homework) and then a three-hour compulsory Bahasa Malaysia class for international students to follow. I had to put together a PowerPoint Presentation for the Monday of the second week. This was another new challenge as previously I had always had somebody else prepare my presentations. It took me most of the weekend to master the programme but somehow I got the presentation together in time.

When Steven would Skype during those first few weeks to tell me of his study problems at university – no doubt looking for a sympathetic fatherly ear – I would respond, "if you think you've got problems, just listen to mine." For the Bahasa Malaysia examination, I crammed as never before. I even learnt 17 Bahasa Malaysia phrases and thought I don't care what the essay question is – these phrases are going in somehow. I think the lecturer was shocked when I got 95% and the top mark, certainly no sign of that potential in any of the classes. Sadly, I only managed a B+ for the Research Methods class but I have earned better grades since.

It was all going well until late December 2012. Then I got Guillain-Barré syndrome (AMAN variant), very rare and not good. The immune system goes haywire after a flu or stomach virus and attacks the nerve ends. Upward ascending paralysis follows. I was very lucky that I was diagnosed and treated promptly. It was though pretty scary being in Intensive Care hooked up to an IV line giving me 12 bottles of Immunoglobulin a day – good antibodies to counter the damage being done by the GBS. My fellow students were just fantastic visiting me with

various gifts – toothbrush, razor, wifi dongle (a real lifesaver for communication), books and fruit. The dragonfruit they brought though did cause a health scare as my urine turned bright pink not long after consumption!

I returned to England because there was no way I could look after myself in KL. I did walk out of the hospital but it was touch and go and I was very unsteady. I needed a wheelchair at the airport – it all felt so weird as I had never had any serious illness in the previous 59 years. It took about six months, including another hospitalisation in England and a lot of gym work, for me to learn to walk properly again and eventually to climb stairs unaided. No longer was I falling down going into pubs! I still have a few minor residuals but I am now pretty much recovered. And when you have been in Intensive Care with people dying nearby or in a specialist neuro ward and you see what many people have to put up with in their daily lives, you realise how very lucky you are.

I returned to finish my studies in January this year with another new group of young students. They were also fantastic to study with and to learn from. It really has been a wonderful experience to go back to 'school' as an aged student and to have the opportunity to make new friendships with so many bright young people.

I have just finished writing my dissertation of 22,000 words on "Myanmar: Changing Priorities". I had written the paper in my head, but unfortunately they wanted it on paper. It was made a little easier because I had undertaken a research internship with Myanmar Institute of Strategic and International Studies in Yangon from May to July as part of my degree programme. Probably the world's oldest intern at 61 years of age!

It was a great experience to be in Yangon at a time of such dramatic political, economic, and social change and to be working and meeting people who now look to the future with much greater hope. Over the past 50 years of military rule and isolation, the country has gone from being having one of the highest incomes per person in Asia to being the poorest in Southeast Asia. Only $20 per person, for example, is spent on health – less than five percent of what is spent in Malaysia and less than one percent of what is spent in Singapore. It may take 20 years for the country to recover and to achieve its potential, but it now has a wonderful opportunity for a new start if the various leaders can find a way forward in what will be a labyrinthine task.

While in Yangon I wrote three papers. One was on "Functional Cooperation in the South China Sea"- this was used as background for a Track II Diplomacy meeting of regional elders (former Foreign Ministers of ASEAN countries and China). I also wrote a paper on Health and Education in Myanmar and another on the Development of Myanmar's Financial Markets. The papers got high-level distribution in the Myanmar government. I was also asked to write an Op-ed for the NikkeiAsian Review – "Myanmar needs to press ahead with its Big Bang".

Reflecting on the last two years, I have realised that both my inner and my outer landscapes have changed. Looking out over the marvellous view across the Straits towards the mainland from my 31st floor balcony is a daily pleasure. I even had a local artist, BiBi Chung, paint me a mural of Broadstairs in Kent where I spent holidays when I was young. Bleak House (which was Dickens's home but called Fort House then) is on the hill. From Bleak House to tropical seas – it's quite a change of vista.

As I come to the end of my Masters degree, I will again need to think about what next. I intend to continue my involvement and interest in Myanmar, but also to enjoy life in Penang.

Malcolm Hanney

"Originally published in *Penang International* magazine, which provides information for those living and visiting Penang. Please see http://www.expatgomalaysia.com for more details."

Repairing Spaghetti Junction!

I've never been much of a night owl, and have always needed my sleep. Even as a child I would often ask to go to bed early. Since I became ill my need for sleep has gone off the Richter scale! On a weekend if I don't set an alarm, I can easily sleep for twelve to thirteen hours, and still be tucked up in bed by ten the following evening!

Needing lots more sleep in itself is not a problem for me. My daughters quite like the fact that we all head off to bed at the same time, and being single I don't have anyone complaining that I'm going to bed too early! Fatigue, however is a massive problem for me every day. I like to use the word "fatigue" rather than "tired" because I feel like a whining child when I constantly complain that I'm tired. I tend to use the term "extreme fatigue" to try and express that it's sooo much more than just being tired, but I still don't think people really understand how it feels.

It doesn't seem to matter how much sleep I get, or whether I had my afternoon nap, the fatigue doesn't go away. My fatigue levels are not always in relation to what I did the day before. Some mornings the minute I open my eyes I know it's a bad day, even if I'd spent the day before doing very little. I struggle with fatigue to some degree every single day, but some days are far worse than others. On these days even the smallest of tasks seem like massive mountains to climb, and I find everything overwhelming.

I don't have a very good understanding of medical stuff, and only got a "D" in my biology GCSE! From what I can make out, the fatigue occurs because my body is so busy trying hard to get messages through my nervous system, in order to carry out normal activities like moving and walking. Because my nervous system has been destroyed by the Guillain-Barré syndrome the messages reach dead ends, and so the brain has to find them a new route. Imagine driving through Spaghetti Junction and every corner you turn you are faced with a "Road Closed" sign, and eventually after trying several different options, you have to come off and take the country roads! Also my body is constantly trying to repair the damaged nerves, which is a full time and tiring job in itself! This is exhausting for my body and consequently it doesn't have much energy left for anything else! I think this is also why my memory is so bad. Since having GBS I've found it increasingly difficult to remember the things I have to do (I now live my life by alarms and post it notes!) as well as things that have recently happened. It's quite frightening when I have no memory of a conversation I'd had only a few days before, or no memory of where I'd gone. It has taken a bit of getting used to, but I now accept that's the way I am, and no longer beat myself up over it.

Luckily my children are wonderful and help me out every single day. I also have brilliant parents and an amazing network of friends, who all chip in. Without everyone's help I wouldn't be able to live my life as I do. All the things that each person does add up to make a huge difference to my life, and I am very grateful.

Right, time for me to put the kettle on, get out my onesie and park myself in front of the TV with a bar of chocolate….. Don't judge me, I'm extremely fatigued I'll have you know!!!

Andie Phillips

If you would like to follow Andie's blog, the link is: Pinklover72.wordpress.com

Branch & Network News

South West England

Saltford Golf Club near Bath very generously provided the venue for The South West regional branch meeting of GAIN on Saturday 21st March 2015. Eighteen people were able to attend, some from as far afield as Kent and Lancashire, and over tea and biscuits we shared experiences of diagnosis and recovery. We gathered ideas for speakers at future meetings. From fundraising at this and previous meetings we are pleased to be able to donate £600 to GAIN charity funds for the purpose of research.

Saturday 24 October 2pm
The next meeting will be held at Saltash Wesley Methodist Church, Callington Road, Saltash, Cornwall PL12 6LA

Yorkshire

The Yorkshire branch meeting was held on the 22nd March 2015 at the Boothroyd Centre in Dewsbury and as always, was well attended with a few new faces.
The guest speaker was Linda Birch from Forget Me Not Holistic Therapy, who spoke about the benefits of reflexology, reiki and massage therapy. Linda owns her own business in the Wakefield area and visits clients in their own home.
One of the GBS sufferers who attended the branch meeting has benefited from Linda's therapies and kindly arranged for her to speak.

The next branch meeting will be on the 18th October 2015 at 2.00pm at the Boothroyd Centre in Dewsbury.

Kent

The Kent Group held its annual Post-Christmas get-together once again at The Woolpack Restaurant, Ashford, on Saturday 10 January 2015.

Unfortunately only fourteen Members were able to attend from the nineteen that were originally listed, as last minute illness, which sadly seems to be doing the rounds at this time of year, took its toll.

However, those that did come enjoyed a 3 course meal from a menu with lots to offer, making a welcome change to the Turkey and trimmings which we have become used to over the past few weeks, and a chance to meet old friends and new acquaintances alike with plenty of opportunities to exchange experiences.

Everyone felt that two or three get-togethers a year was about right and we should continue in this manner – we are looking forward to the delicious cream tea in the summer.

Saturday 27 June 2.00 - 4.00pm
Cream Tea, St. Nicholas-at-Wade

For further details contact Gill Ellis:
support@gaincharity.org.uk

Scotland

A very enjoyable and successful fundraising Valentine's Dinner, organised by Anne and Ian Bennett, was held on Saturday 14 February. See page 8 for details.

Saturday 3 October
11.00am – 4.30pm
Meeting and AGM
at the Holiday Inn,
Glasgow Airport

West Midlands

A group of us from the Midlands Branch met up on Saturday 29 November for a very enjoyable evening at the Skydome Arena in Coventry to watch the Coventry Blaze Ice Hockey team.

After a meal at a local restaurant, we set off to the arena to watch Coventry Blaze play Sheffield Steelers who, being top of the Elite League, were favourites to win.

The game is split into three periods, with various entertainments in between. In the first period Steelers took the lead 1 – 0 but Aimee Dawson (who had been so helpful in arranging this visit) came to see us during the break and assured us that Blaze were playing really well.

She was proved correct when in a very exciting, fast action 2nd period, Blaze scored five times in quick succession and ended the game with a magnificent 6 - 2 win. The atmosphere in the arena was brilliant.

After the game, Aimee brought Mike Egener from Coventry Blaze to meet us (Mike had GBS in 2013). He stayed and chatted for about 20 - 25 minutes, signed our programmes and joined us for a group photograph. He is now assistant player coach for Coventry Blaze, but was unable to play as he was recovering from a broken bone at the base of this thumb.

Having enjoyed the first game so much the Midlands Branch, including new members to the group Colin and his family, made a second visit to Skydome on Saturday 7th March. Mike was back playing for The Blaze and they beat Edinburgh Capitals 5-0.

Again, everyone really enjoyed the evening and it was good to see Mike Egener playing. We would also like to give our full thanks to Aimee Dawson for her help.

The James Cook Gathering, Teesside

The James Cook Gathering met on Thursday 29 January at the Beefeater Restaurant, Morton Park. It was well attended and included guest speaker Jan Burden from Durham County Carers.

Jan began her presentation by outlining the work and range of services provided by Durham County Carers and emphasised that similar services are replicated across other local authority areas. It was felt that more information about carer services should be available to patients on discharge from hospital.

The James Cook Gathering of GAIN now has a facebook page www.facebook.com/jcgathering.

Please get in touch with head office for details of future meetings.

Lancashire & Cumbria

It was great to be able to welcome three newcomers to the quarterly Lancashire & Cumbria Branch meeting and AGM on 14 March. After the brief formalities of the AGM we were entertained to an informative and amusing talk entitled “Life of a Sewer Rat” from the retired Chief Waste Water Engineer for the NW of England, who had been responsible for 49,000 miles of sewers from Crewe to Carlisle. It was full of amusing anecdotes, which several members of the audience were able to add to. We then got on to our regular Sufferers & Supporters Forum when we exchange experiences, questions, and tips on living with GBS & CIDP, before finishing off with draws for the 100 Club and raffle, sale of Sybil’s lovely preserves, and tea and cakes. Future meetings are on 6 June (talk on acupuncture), 26 Sept, and 5 Dec all at Bilsborrow Village Hall on the A6 north of Preston, commencing at 2pm.

Can you help us claim a

£27,709.50

TAX REBATE?

It would make a huge difference to the vital work that we do if we could claim back this tax.

If you are a UK taxpayer, by completing the form over the page you can increase the value of your donations at no extra cost to you. Through the Gift Aid scheme, the government will add 25p to every £1 of all qualifying donations we have received in the last four years. Please let us know if we can claim Gift Aid on your donations by completing the form on the back of this page and returning it to:

GAIN
Woodholme House
Heckington Business Park
Station Road, Heckington
Sleaford
Lincolnsire
NG34 9JH

You can also make a Gift Aid declaration by calling GAIN on 01529 469910.

Many of you have already completed a Gift Aid declaration but if not – please spare us a few minutes of your time so that we can claim this money.

If we don't claim it, we lose it.

Thank you

giftaid it

What is Gift Aid?

Gift Aid makes your donations go further without costing you a penny

Gift Aid is a scheme whereby the government lets charities claim back the tax that supporters have already paid on donations made

In order for us to be able to reclaim the tax, you must be a UK taxpayer. You must have paid enough tax in the financial year to cover the amount we will claim

If you are retired or do not work you are likely to pay some form of tax on your savings or pension, so you may still be eligible

A declaration can cover the last four years' donations and any future donations, until you tell us otherwise

gain Guillain-Barré & Associated Inflammatory Neuropathies

gain form

Gift Aid Declaration

Guillain-Barré & Associated Inflammatory Neuropathies

Please treat as Gift Aid donations all qualifying gifts of money made today, in the past 4 years and in the future.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax to not quality. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Donor's details

Title ..... First name..... Surname.....

Full home address .....

.....

.....

Postcode ..... Date .....

Signature .....

Please notify us if you:

- Want to cancel this declaration
- Change your name or home address
- No longer pay sufficient tax on your income and/or capital gains.

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

Gifts in wills

What will your legacy be?

A gift to Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) in your will is an extra way of looking after the people you care about who have been affected by GBS, CIDP and associated inflammatory neuropathies: your own family, friends or even people you'll never know. People you will want to help because you know how hard it can be when families are affected by these rare and often devastating conditions.

Your gift will help make sure we can be there for all of them if they ever need us, whether that's 10, 20 or 30 years from now.

How we use these gifts

These gifts come in all shapes and sizes. Big ones, small ones – £200, £3,000, £20,000, £110,000, 20% or 100% of an estate or anything left over after the other gifts have been made.

We use these gifts to give support to people affected by the conditions when they most need it:

- a recovered patient will listen and help using their own experiences;
- up to date literature to inform the patient and their loved ones;
- medical information packs for hospitals and GP surgeries;
- research into the conditions to try and find a future where no one has to suffer.

> "these gifts come in all shapes and sizes

We understand that when making a will your family must come first but even a small gift will help us give every person affected by GBS, CIDP and associated inflammatory neuropathies, and their loved ones, the best possible support in their hour of need.

For more information email:
fundraising@gaincharity.org.uk

or look at our website: http://www.gaincharity.org.uk/wills-and-legacies/info_55.html

How to leave a legacy for our work

Please ensure your will includes our full name, registered office address and registered charity number.

Guillain-Barré & Associated Inflammatory Neuropathies
Woodholme House, Heckington Business Park, Station Road, Heckington, Sleaford NG34 9JH

Registered Charity in England & Wales 1154843

If you have already left a legacy for the GBS Support Group

Following the change in status and transfer of all assets and liabilities to the new Charitable Incorporated Organisation (GAIN), the GBS Support Group has been registered on the Charity Commission's Register of Mergers which means that a legacy left to the GBS Support Group will be treated as if it had been made to Guillain-Barré & Associated Inflammatory Neuropathies.

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

gain
Guillain-Barré & Associated Inflammatory Neuropathies