gain4all

Issue 10

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

Hair today – GAIN tomorrow see page 10

www.gaincharity.org.uk

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

____ =

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:
g4all10

☐ 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

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

CONTENTS

gain
Guillain-Barré & Associated Inflammatory Neuropathies

Back cover picture courtesy of Phil Graham

gain

Woodholme House
Heckington Business Park
Station Road
Heckington
Sleaford
Lincolnshire NG34 9JH
Tel: 01529 469910
Email: office@gaincharity.org.uk
Office Enquiries: 9.00am – 3.00pm

FREE HELPLINE:
0800 374 803 (UK)
1800 806 152 (ROI)
Registered Charity 1154843 & SCO39900

gain4all

gain-in-numbers

Quarterly update 1 April – 30 June 2016

Volunteers

19 Helpline
125 Support
10 Applications being processed

New Users

68 registrations

Helpline Calls

261

Request for Peer Support

23
(includes phone call or visit)

Current users/ subscribers breakdown

Magazine subscription type:

Postal Magazine (UK)	733
Postal Magazine (Ire/Eur)	13
email Magazine	1389
No Magazine	38
Total	**2173**

Voting Members

287

Direct Debit

97 Subscribers

Support Related Publications

Patient Information Packs	**59**	(excludes information requested and sent by email)
Communication Cards	**3**	(produced in house for hospital use)
Medical Information Packs	**28**	(plus extra booklets and Quick Guides for hospitals to pass on to patients)

Fundraising and Donations

Donations Received	**£5679.50**
Fundraising Activity	**£27775.43**
In Memory	**£2156.03**
Research	**£200.00**
Little Box	**£281.18**
Gift Aid (Gross)	**£8299.57**
Sale of Goods	**£262.79**
Legacies	**£0.00**

Social Media

Facebook Group	**1703** members
GAIN Facebook Page	**718** Likes
Twitter	**388** followers

GAIN Website

Total Sessions **6446**
(new sessions 75.5%, returning visitors 24.5%)
Users **5107**

Raffle winning numbers: 15689, 14070, 11084, 05073, 13378, 05967, 15882

The deadline for submissions is 31 October 2016. Please forward all articles to **gain4all@gaincharity.org.uk**

GLASGOW gain2gether 2016

A week in Glasgow

The Inflammatory Neuropathy Consortium 2016 was held at the University of Glasgow, Scotland and Guillain-Barré and Associated Inflammatory Neuropathies was part of the event.

Caroline Morrice, Director and David Wada, Treasurer were there from the beginning with a GAIN stand telling everyone about the work of the Charity. Our publications were a great hit with medical professionals around the world, with many asking if they could translate for use in their own hospitals. Of course we said yes, safe in the knowledge that all our publications are written and regularly reviewed by the GAIN Medical Advisory Board.

GAIN were lucky enough to be able to attend all the plenary sessions as well as the social events, which were a great place to meet those involved in all the aspects of peripheral neuropathies. This lead to discussions with pharmaceutical companies and more opportunities for GAIN members to get involved in studies and research to shape the future for those affected by these illnesses.

> **"Our publications were a great hit with medical professionals around the world, with many asking if they could translate for use in their own hospitals."**

A full write up of the INC 2016 meeting will be available on their website in due course http://www.pnsociety.com/inc-2016 but here are a few of the highlights from Friday, which was the GBS day.

2016 is 100 years from the publication of the famous description by Guillain, Barré and Strohl which over time has become known by the names of Guillain and Barré and more often is referred to as GBS. GBS today is well known around the world with the incident rate a steady 2 cases per 100,000 - that means approximately 100,000 cases per annum worldwide!

The early records show case studies from the trenches of WW1 where soldiers were showing signs we all recognise, pins and needles, motor weakness in lower and upper limbs and improvement starting after 1 month. Treatments that the 3 Doctors recommended included "absolute rest, massage of the upper and lower limbs and injections of strychnine and soda of phenyl salicylate". So not that much different to today – admitted to hospital, given physio and using experimental medicines!

A friend of Joseph Heller summed up why we know of it as Guillain Barré and never refer to Strohl. When asked whether he knew about Guillain-Barré he replied "No, I never heard nothing about it (sic) – but when they name any disease after two guys, it's got to be terrible!"

Professor Richard Hughes spoke of his life with GBS, recognised as one of the most important GBS researchers who made seminal contributions during his career. Richard spoke of some of his contributions to research over the years, some of his work featuring in the top 10 leading articles on GBS which were discussed later in the day. Richard also helped in the setting up of the GBS Support Group in the UK back in 1985 and in 2007 he raised the Inflammatory Neuropathy Consortium to support international research on GBS.

Glennys Sanders, Founder GBS Support Group, gave an account of the patient perspective along with Estelle Benson, the Founder of the GBS-CIDP Foundation International. You can read Glennys' story a little later on.

With numerous interesting talks on subjects including Axonal GBS, Gangliosides and anti-ganglioside antibodies, IGOS, animal modes of GBS, delivering specialist care to GBS Patients, GBS and Zika virus and GBS in children, it is difficult to pick out just a few to focus on.

So focussing on Global perspectives we heard about GBS in children and learnt that the incidence may depend on the country of residence

- Western countries 0.38 per 100,000 per year
- Asian countries 0.54 – 2.27 per 100,000 per year
- Bangladesh 1.5 – 2.5 per 100,000 per year

And problems in children are universal

- Delay in diagnosis
- Prediction models not available

So what for the future

- Large prospective cohorts worldwide
  - Clinical presentation
  - Treatment
  - Long-term outcome
  - Demographic differences
- Developing prognostic models for children with GBS
- International collaboration – a unique opportunity to compare the differences between countries and improve the care for children with GBS

Later in the day there was a quiz to see who knew the most about GBS – suffice to say our Trustees and staff were not the winners!

We rounded off a busy week with gain2gether Glasgow – a mixture of GAIN members, representatives from patient groups around the world and pharmaceutical companies.

Our Chairman, James Babington Smith, opened the event welcoming everyone to the day. James acknowledged the financial contribution that had been made to the charity in memory of Candice Roberts, in excess of £35,000.

David Cornblath, gave a little history of the disease from Landry's time to the current day. He particularly focussed on the amazing work of Professor Richard Hughes, and some of the key personalities in the field as well as in the Support Groups. He was asked why the Netherlands were doing so much? The answer was simple, in a flat small country it is easy to travel around and form a study group.

John Goodfellow, gave a talk on the GBS100 monograph which celebrates a century of progress in Guillain-Barré syndrome. A copy will be put on the website, and there may be a few available firstly to those that attended the gain2gether but did not get a copy and then on a first come basis.

Glennys followed with her story of founding the Support Group…

"Nearly 35 years ago when I developed Guillain-Barré syndrome very severely I could not have foreseen how it would change my life and that I would be standing here talking to you. Difficult putting it in the few minutes allowed.

The sudden traumatic and devastating circumstances of being completely paralysed, only able to communicate with blinking my eyes, completely reliant on a ventilator, unable to touch my 2 young sons and husband, unable to tell anyone my fears and frustrations made me experience so many emotions. Fears for the future. In spite of these circumstances it changed me for the better. I am more tolerant, patient and understanding. I have learnt so much and met such lovely people.

I shall never forget the loneliness and isolation. Not having anyone who understood how I was feeling. No information, no encouragement or reassurance that I was going to improve.

I can remember vividly, whilst in intensive care, thinking that if I was feeling like this with a supportive husband and two young children to inspire me to get better, how sufferers on their own must feel. I had so much time to think during the four and a half months on a ventilator. There must be a reason. Being an optimist I believed something positive could be achieved. I promised myself that when I got better I would find information about the illness and offer reassurance, support and encouragement to those currently suffering. I had a vision that everyone who requested help would get it and have contact with others who understood their feelings and despair. Remember this was before the internet - only slow mail and telephone.

It was over two years later that I could start researching whilst at rehabilitation at Headley Court. Half of me wished to forget my promise to myself. The other half knowing that support and information was needed. I still had not met anyone else who had suffered GBS.

I felt I needed to be mentally stimulated. Physically I was relearning to walk and do all the things that one normally takes for granted. I knew I was not going to be able to return to secretarial work for a long time as my fingers and hands were so weak. I was unable to pursue my interests in tennis and squash so needed something to motivate me other than my disabilities.

I telephoned various neurological hospitals but each time seemed to get the same answer "We were doing research but have run out of money" - not much has changed over 32 years! I received a letter from Nottingham asking to visit a sufferer. Her husband remembered he previously had an American secretary who had worked for someone with GBS. He contacted her and was sent a book about GBS produced by a Support Group in the USA. I could not believe the words. It was just how I felt - the same frustrations, fears and loneliness. I kept reading it over and over again. It was like a Bible.

Whilst at rehabilitation I met two other sufferers. With renewed vigour I contacted the US for information how to start a British Group. They were so helpful and encouraging sending posters and books free of charge. They told me Dr Richard Hughes at Guy's Hospital was involved in research and was a member of their Medical

Advisory Board. He was so pleased to hear my plans to set up a much needed Support Group. He was very encouraging and supportive and has continued to be a great source of knowledge and help.

I knew I had to gain publicity. I wrote to every District Health Authority and all forms of media. I was thrilled for my name and address to be given out on the Jimmy Young medical programme - who is old enough to remember Jimmy Young?! The next day I received 17 letters from desperate sufferers and families. I was overwhelmed. Within six weeks I had received 75 letters and realised there was a need for a meeting. Dr Hughes kindly arranged for a training room to be used. How many people would attend and travel to London? Should catering be provided? The venue was changed twice to accommodate the growing numbers - finally held in the prestigious Lord Roben's Suite on the 29th floor of Guy's Tower. 110 people attended, a voluntary committee formed, donations received. All had one thing in common and we all learnt so much from each other. It was the first time sufferers had spoken to others.

It was so satisfying and rewarding. All my doubts and fears were expelled by the support and gratitude of those present. I no longer felt I was running the Group alone, though I continued to be secretary, treasurer, fundraiser and publicity officer for a few years. Our home was used as the office for the first ten years until we could afford to rent an office and employ a part time administrator. Now GAIN have three members of staff and an established office with relevant equipment tor today's technology.

I visited patients and gave talks to medical professionals all over the country. We developed local contacts nationwide, an awareness programme, raised funds for research, gained publicity from various radio and TV programmes. I was proud to be asked to join the steering committee of the Neurological Alliance, as a response to the Health of the Nation document and a standard plan for neurological care, to include GBS and the All Party Disablement Committee of MP's. CIDP was later added. I became involved with the

European Plasma Protein Association and the Inflammatory Neuropathy Consortium and International Director of the GBS/CIDP Foundation International which gave the opportunity to travel.

I worked voluntarily developing GBS/CIDP Support Group of UK and Ireland over 25 years. I could not have done it without the continued support of my husband, Howard, who paid the postage and telephone bills in the early years and the unfailing support of members of the National Executive Committee over the years. I have met so many amazing, committed and lovely people.

Though I was awarded the MBE for my services to Guillain-Barré in 2000 I could not have achieved it without the support of so many people."

Rob Hadden then went on to explain why support groups were so important and how peer support helps others who are struggling to come to terms with the disease. GAIN can also help with reliable patient information, arranging gain2gethers around the UK and supporting volunteers. The patients and recovered patients can play a vital role in studies and research providing data to support the work of the researchers. There are a number of studies and trials being undertaken and GAIN have members taking part in several of them.

Patient and geriatric consultant Ana Talbot gave a very moving account of her life with CIDP both at home and at work.

Professor Hugh Willison gave an update on the students and medical teams that the charity has funded over the years – most of them had joined us for the day which was great. Susan Halstead focussed her talk on Zika virus, Govind Chavada gave an update on IGOS (partly funded by GAIN) and how they are now looking at factors that were not known previously. Amy Davidson looked at what the future held in terms of treatments and Angie Rupp talked about GBS in animals.

Immediately following lunch, we all took part in the exercise for all session, which proved you can raised your heart rate, burn a few calories and keep fit without getting out of your chair thanks to Santo Garcia, President of the Foundation International. The video can be viewed on our website! Lesley I have it on my phone to download

We were given a preview of the play "Getting Better Slowly" – the account of one person's battle with GBS. This play will start touring in the Autumn so keep an eye on Facebook and the website as more details are released.

The afternoon was rounded off by a rising star of the neurology world Simon Rinaldi who gave us his predictions for the future.

During the day, the Trustees, staff and members made a presentation to James Babington Smith as he stepped down as Chairman of the charity. A decanter, glasses and something to fill them with was presented to him by our Patron Sir Ian Macfadyen.

We rounded off the afternoon with the Annual General Meeting, all motions previously notified to members were carried. At a Board meeting following the AGM it was agreed by all the Trustees that Chris Fuller would be the Acting Chairman and Adam Pownall was co-opted to the Board as a Trustee. Members interested in applying to become a trustee should contact Caroline Morrice, director@gaincharity.org.uk

The Saturday was rounded off with a meal and a further preview of Getting Better Slowly.

Mission Accomplished

Jack Robinson had a mission - to donate his hair to the Little Princess Trust, to support his brave cousin Kieran who was diagnosed with Guillain-Barré syndrome and to raise funds for GAIN.

Kieran's mum, Jackie recalls:

In September 2008, when Kieran was four we remember him complaining of being unable to flush the toilet which was a button, his hands "felt funny" and he couldn't push the button down. He had also been tiring easily throughout the day with back pain at night and no matter what pain relief we gave him it didn't have any affect, he was in agony. Kieran's condition deteriorated over the next three to four days, particularly his movement and doctors were completely baffled thinking he had a virus and the back pain was due to a fall.

Kieran seemed to go downhill in front of our eyes, he could barely walk, kept falling over and his balance was off. We went back to the GP and again, were told it was viral but I knew something wasn't right and demanded a second opinion. I think we saw every doctor, consultant etc under the sun in A & E - MRI scans, CT scans, X-rays, blood tests, you name it but they couldn't understand what was going on or what it was. He was admitted, it was terrifying. Once in hospital, I fully expected a fast diagnosis but it took another three days of more tests including lumbar punctures, before the final nerve conduction test, finally confirmed GBS. Kieran was in so much pain – it was heart breaking.

They continued to monitor Kieran closely and thankfully did not need to be ventilated. They decided not to treat him with intravenous immunoglobulin or plasma exchange as they felt it was too risky at his age; they also believed it was beginning to plateau and so confirming it was a mild case.

Kieran was in hospital for two weeks, we had a room to ourselves and on the second week, a physio came to help with his movements and to build up his strength. He lost a lot of weight and wasn't particularly eating so the dietician was also involved.

aising reports

There was a lot of input once we were home with physio, OT, dietician etc and regular check-ups with his consultant. Kieran's balance took a while to come back, he had to basically learn to walk again, gross motor skills as well as fine motor skills, hand and eye co-ordination with pincer grip for fastening buttons, holding cutlery, a pencil, everything you take for granted really! He had 13 different medications/pain control to take and he tired very quickly.

It took over two years to fully recover, Kieran seemed to make good progress, but would then plateau for a while and even take steps back. Pain in his feet was always a big problem as was fatigue, it took years for his running to become "normal" and his confidence took a huge knock. He would be very frustrated at not being able to keep up with his peers.

I am not actually sure when Kieran was classed as fully recovered, but to look at him now you wouldn't have any idea. He has been left with some residual weaknesses, he lacks stamina and speed and still has bother with fatigue if he has a lot on physically. Now and again he will complain of pain in his feet, he has pain with his wrists if doing written work for any great length of time and has his own way of holding a pencil or cutlery. We have found solutions and as Kieran gets older there will be other obstacles I am sure, but we will find new solutions and Kieran will continue to take it in his stride.

Due to Guillain-Barré syndrome being so rare, particularly in children, not many medical professionals had experience in dealing with it and so most of the time, couldn't answer our many questions. We had lots of support from family & friends but the internet became our source for information and guidance. This is where I found GAIN. They were a superb help, posted out information leaflets, a specific child friendly booklet for Kieran to help him understand and also put us in touch with another parent through email who had shared a similar experience.

"For GAIN, a special thank you to them from myself and the family for the help and support they gave us in the beginning and still do through their facebook page where parents/carers/family and survivors can chat and share experiences and help answer one another's questions. When you are initially told how rare it is you feel so isolated, that changes when you jump online - it doesn't seem so rare at all and everyone's input is fantastic. "

The Mission

It was important to both Jack and Kieran to raise awareness of GBS, to help those, like Kieran, who have been affected by the syndrome, raise funds and after hearing about The Little Princess Trust, Jack also wanted to grow his hair so long that it could be put to good use and made into a wig for a little girl who had lost her hair due to cancer. So in 2014 Jack started to grow his hair "it was not an easy job for a blue eyed boy!" said his Mum Lorna, "he has been called a girl - daily, has endured the repetitive dose of 'ohh, when are you going to get that hair cut', been teased by other children (who don't know him) for having long blonde hair, been mistaken for his sister Emily and even been asked to leave the boys toilets because he has been mistaken for a girl. That one, really, really hurt. But throughout, he kept his resolve and his humour to continue with his mission."

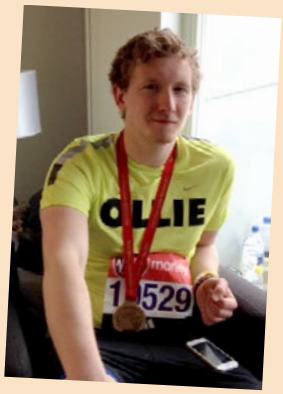
The June 2016 haircut was no ordinary haircut and quite an emotional event. Jack dressed up as Thor and was supported by his family and friends - Chewbacca (East Ayrshires Provost!), Batman, Batgirl and Captain America from Party Palz. His golden locks are now on their way to be transformed, Jack has his 'boy' status back again and over £1700 has been donated to GAIN.

"The cousins were united in their mission and my goodness did we all GAIN a lot! Jack seems a different boy these days, not only because of the short hairdo, but also confident in himself that he's completed his side of this mission. Kieran had the hugest smile throughout the whole event, quite the confident speaker talking to Alan Brown MP (who also joined in with fundraising), being splashed all over the local press and indeed as part of raising an EDM in Parliament! It's been a WIN - WIN all round, for the boys, for raising awareness and we hope for GAIN and the people that need their invaluable support just as Kieran, his mum Jackie and family all did, not so long ago."

Lorna Reid

"Kieran and I would like to say a massive thank you to both Lorna and Jack for all the hard work they have done. For thinking of GAIN, raising awareness and the fantastic amount that has been donated, absolutely amazing."
Jackie Stewart

24 April 2016
Virgin Money London Marathon

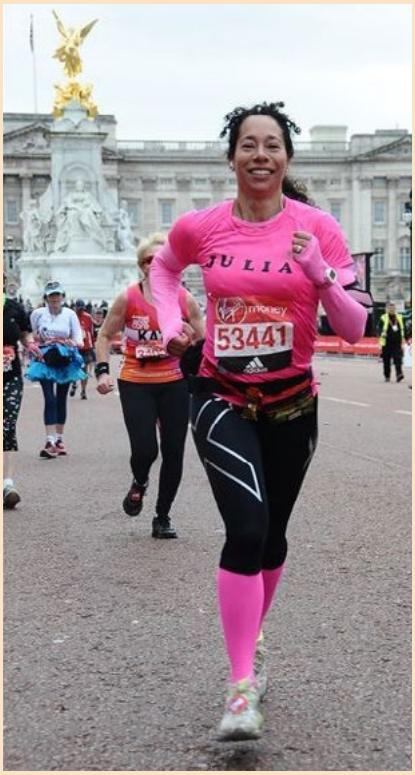


Oliver Deane (right) completed the marathon in 4:05 raising money for both GAIN and Alzheimer's Research UK.

"In August 2013 I was struck down by GBS which completely paralysed me. I was in hospital for six months and it took another two years of rehabilitation to get me back to some sort of normality. I was so lucky to have such a loving wife, my caring children and my close family and friends to help me through this difficult time.

I ran the London Marathon to raise awareness and to give something back to the people who got me through it, namely the staff at Chase farm Hospital and Northwick Park Hospital and a special mention to Heather Wilson from the Royal Free Hospital who diagnosed my condition at such an early stage, making it possible to recover so well."

Ever Loukaides



"Well I had a great time running the London Virgin Money Marathon.

I did it in 5:48. It was an amazing experience! I loved every moment of it. The crowds were great and give so much support which helps you along, and it was wonderful to enjoy the great sights of London.

I am also thrilled that I managed to do it after having GBS in 2012. It's amazing how the body can repair, recover and adapt to new challenges.

Hope it might inspire/help someone else."

Julie Elliott

24 April Southampton Half Marathon

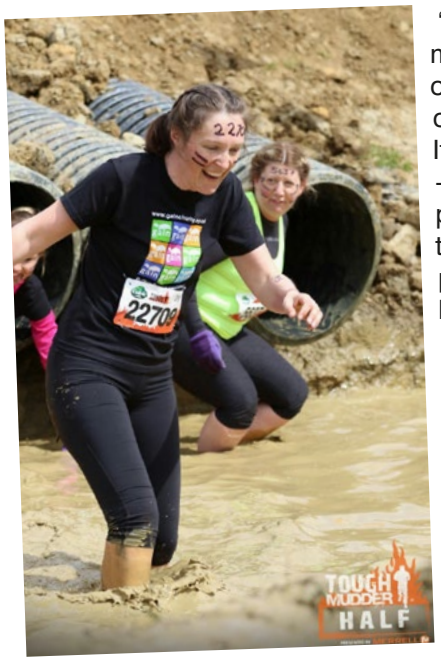
Tony Cummings completed in 2:03

"Around this time a year ago, a good friend of mine was unlucky enough to get Guillain-Barré syndrome, a condition I'd never heard of. I then witnessed first hand the debilitating impact it has as my friend spent months in hospital and has pretty much had to learn to walk again".

London2Brighton

Stephanie Urquhart and her walking buddy Kaytie Lee completed the London2Brighton 100km challenge and crossed the Brighton Racecourse finish line, together, in a time of 27 hours and 39 minutes. Stephanie, who had GBS in 2005 said "it was an incredible

Tough Mudder Half North



"It was great fun; so much mud and six miles of it! We managed every obstacle which was great. It's all about camaraderie - taking help from the person in front then turning and helping that person behind you. Really rather like our GBS journey.

I had lots of friends who supported me during my son, Owen's illness and having seen the effects first hand they were all keen to donate. I was staggered at how much I raised."

Taflyn McLoughlin

Great North Swim 2016

"Unfortunately due to ill health last year I was unable to take part in the challenge I set myself of completing the one mile event in the Great North Swim in Windermere. I've just been given the go ahead to start training again so here goes - I'm giving it another go this year and will be raising money for GAIN. For those of you who don't know my story, GBS is the illness that paralysed me from the neck down in October 2009. I am one of the lucky ones who has made a full recovery, unfortunately this is not always the case. Wish me luck and thank you in advance."

Michelle Blakely

Congratulations to Michelle for completing the swim on Sunday 12 June this year.

Challenge

experience and I've been truly humbled by so many people giving support and donating and even a few asking questions about the condition itself. I honestly never thought my body would be able to do something like this and feeling pretty darn grateful for a lot of things, even if my boots and rucksack didn't quite survive!"

Four Countries in Four Days

GBS (Miller Fisher) survivor Christopher Burbidge took part in a four day, four country, 250 mile cycle challenge earlier this June. The four days took in the Ardennes region of Belgium, Luxembourg, France and Germany and involved over 20,000 feet of climbing. In total 24 riders took part, raising money for several different charities but Christopher was riding for GAIN, having spent time in Leicester hospitals with Miller Fisher in early 2014. At time of print, fundraising for GAIN is pushing towards £3000, mainly due to friends, work colleagues and a very generous £500 donation from Christopher's employers, Cordant Group. Christopher would like to thank everybody who has sponsored, supported, encouraged, dragged him up hills and through torrential rain. The weather in Belgium was certainly not kind !

I'M GOING NOWHERE!

GBS survivor Phil Graham and his wife Janet visited GAIN Head Office at the end of May to present a fabulous cheque, being the proceeds from Phil's book I'm Going Nowhere! launched in November 2015.

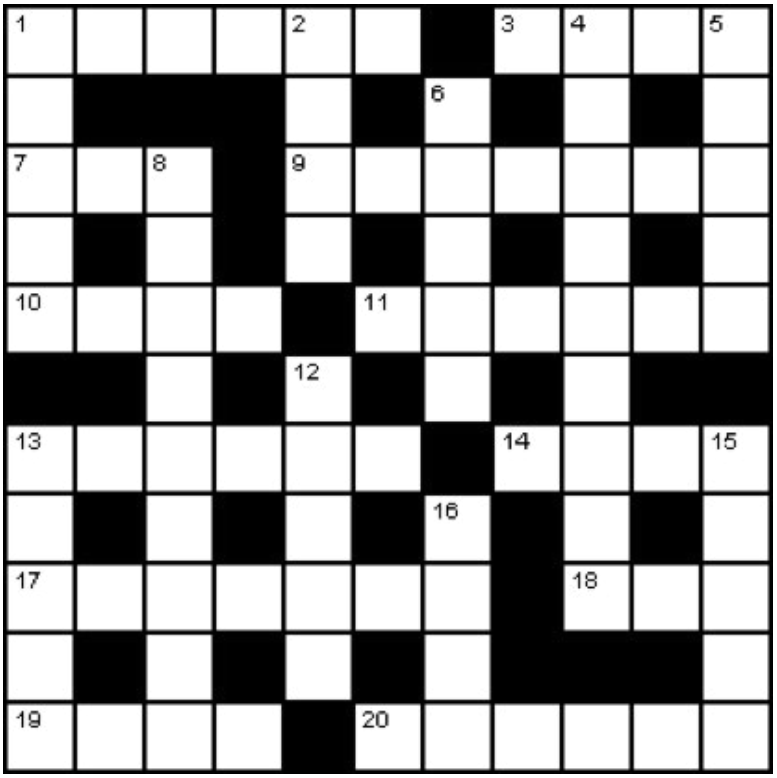
"I am not a professional writer", said Phil. "My book is written in the style in which I speak. I pull no punches whilst offering highly personal observations of life as a totally dependent patient in a busy NHS hospital and as a slowly improving disabled person following my discharge."

Of the book sales Janet explained, "the response to I'm Going Nowhere! has exceeded our wildest expectations. Not only have fellow GBS survivors and their families bought books but so have a number of non-GBS readers from around the UK and worldwide."

A limited number of books are still available (£9.99 plus p+p via paypal, bank transfer or cheque) and can be ordered directly from: Phil Graham, t: 01388 602479, e: phil@filmar.co.uk

Puzzles Page

Puzzles Page – fancy trying to win one of our new range of gift items? The first 10 correct answers to the 2 puzzles will win a prize.



Across

1. Male relative (6)
3. Gem (4)
7. Chart (3)
9. Sagacious (7)
10. Challenge (4)
11. Relating to bears (6)
13. Accolade (6)
14. Children (4)
17. Long flag (7)
18. The night before (3)
19. Extinct bird (4)
20. Choice (6)

Down

1. Wanderer (5)
2. Not difficult (4)
3. Steep cliff (9)
4. Svelte (5)
5. Drama set to music (5)
8. Pilfered (9)
12. In front (5)
13. Lukewarm (5)
15. Rear part of a ship (5)
16. Pace (4)

SUDOKU CHALLENGE

1		8			6	4		
		6		9		8		7
5								
2	6	9	5				8	
			4		9			
	8				2	7	9	1
								5
6		4		7		2		
		1	2			9		3

Just Very Unlucky

Today, having returned from a brilliant week in Spain with my husband, daughter and two beautiful granddaughters I scurried about opening mail, ringing friends, washing, shopping visiting my neighbour and finally driving to 'The Crown Hotel, where I am a member of the gym! As I swam I reminisced…. the turquoise sea…. helping Naomi jump through waves whilst hanging on to the tiny hand of Alice, almost two years old, who, fearless, simply wanted to dive into the water! Who would have thought I could be so lucky!

'You were just very unlucky!' Terry, my partner, whispered as I lay completely motionless in hospital. It was August in the year 2000 and we had returned from another Spanish holiday. Although I was in excellent health generally, I had been troubled by an irritating cough throughout our visit and while we were away I'd had a serious stomach infection for two days. I put this down to either the local water or some chicken we had on a barbecue. This infection had cleared up but this day, as I had tried to unpack, my hands became tingly and so eventually I drove to the surgery where my doctor assumed I had taken too much cough medicine. Within hours my whole body felt weak and I could only just manage to pick the phone up to ring again. Still diagnosing this as a 'virus' my GP suggested I go to bed. By the end of the day my legs would no longer support me and I was unable to move my fingers to phone for help. Luckily, as I lay by the phone, Terry came home and immediately rang 999 but when the ambulance driver rang my doctor she told them to carry me up to bed and she would come down to the house after her surgery. By the time she arrived I was completely paralysed and I was taken to hospital. My condition rapidly deteriorated and after a lumbar puncture was diagnosed with possibly having GBS and I was given a transfusion of immunoglobulin. I remember the terror as they monitored my breathing which was becoming increasingly weak and eventually it seemed like a relief when I was given a tracheotomy.

The next two months seem like a blur now but I remember the feeling of complete helplessness, absolute reliance on the excellent nurses and doctors at Harrogate intensive care unit and the scary reality combined with morphine induced nightmares. I remember seeing a clock and watching as minutes seemed like hours and being so aware of the conversations of the staff around me. I felt trapped and out of control! My feet were splinted and physiotherapists gave me regular physiotherapy. Before being transported back home to Scarborough hospital the doctors performed a small procedure so that I could speak after

weeks of silence. During this whole time my family had been a fantastic support which involved massive disruption to the lives of my daughter Jennie and Terry who actually gave up his job temporarily.

> "For four long months visiting times came and went and I was so happy to see my friends and family who continually gave me encouragement."

Eventually I was taken back to the stroke unit in Scarborough where I began to regain tiny amounts of movement - G B S Getting Better Slowly! Life was regimented by doctor's rounds, drug rounds, bright lights and hospital smells and sounds. For four long months visiting times came and went and I was so happy to see my friends and family who continually gave me encouragement. Terry used to arrive every evening with some entertainment and at one time was playing 'bingo' with all the patients in my ward which was no small effort as no one could move! We used to laugh night after night as he rushed around helping patients cross their numbers off and giving prizes! One evening, to the amazement of everyone, he actually proposed! There was a huge cheer when I accepted!

Meanwhile plans were being made to find long term care for me and evidently, at one point, a care home was suggested because my house had steep steps and no disabled access. However, with great difficulty, Terry and David, my cousin, managed to construct a concrete wheelchair route through our garden and following this the occupational therapy team installed a hospital bed, a chair lift, two hoists, a bath chair, a commode and many enabling pieces of equipment around my home. During the day I was taken care of by many wonderful carers who literally looked after all my needs as initially I was still incontinent and unable to move much. At night Terry or my daughter Jennie looked after me and my friends and family made massive efforts to make life bearable by taking me to hear music at pubs, visit the pictures, go out on shopping trips in my wheelchair etc. etc. Although it was exhausting, I was helped enormously by being taken to a swimming pool and lowered down in a hoist where I could stand using the water as support. Life was never dull and there were many very amusing incidents. Every morning each carer had their own way of blow drying my hair, putting make up on etc. so I always looked different! Once, by mistake, I had my teeth brushed with anusol rather than toothpaste! By the time a year had passed I was beginning to gain far more strength and slowly but surely began to take weight on my legs. Like a toddler I began to walk, learning all the moves for the first time. My first independent step was one year and two months later when I took a step on the beach on a visit to Seahouses in Northumberland. At this point I was still very dependent on a zimmer frame and other people. As well as attending physiotherapy and visiting the hydrotherapy pool I was determined to make as much of my life as possible but everything was such an effort especially for the people around me. Gradually

the movement in my arms, wrists and eventually hands and fingers returned and many hours were spent practising hand exercises using rubber bands, rings and pegs of various strengths.

Before the illness I had been encouraged to take out a critical illness insurance which was supposed to have paid me some money if ever I couldn't work. Although I was off work for two years the company refused to pay anything to help because GBS was not on their list of illnesses!

During this unbelievable time in my life, after months of determined effort to get better and having even tried spiritual healing once, one of the best pieces of advice I was given by a doctor was 'Anne, you would eat greek donkey poo if someone told you it would help, but it wouldn't make you get better any quicker!' We used to laugh, in the later months of my recovery, as I could walk very enthusiastically, to where I wanted to go but when I arrived I still needed help to perform day to day tasks. One of the very amusing incidents was when Terry put me on a train in York to visit Jennie in Birmingham where she helped me off at the other end. Unfortunately, by mistake, she picked up an identical 'black' suitcase off the train and when she got it back to her house she asked me why it was full of artist's tiles and paints. Poor Jennie had a week trying to track down and return this case to an artist as well as having to contact British Rail to try to retrieve my case from Portsmouth where it had ended up. At this point I had to wear special clothes such as elasticated waist skirts and slip on shoes. I had button fasteners, zip pullers, bottle openers, specially designed knives, forks and plates which were all in my case! We had to try to find suitable clothes and find ways to survive a week in Birmingham.

My main aim, after two years of 'getting better slowly' was to return to my career as a primary school teacher with which I was helped by a scheme called 'Access to Work' which enabled me to teach full time with some additional hours given to a few amazing assistants who helped for a few hours a week with display and preparation as I still found fine motor skills challenging at this point. I found many simple ways to compensate for my still slightly weak hands and I was literally a 'bag lady' as I used a shoulder bag or trolley to enable me to carry small objects around. The head teacher, children and staff were amazing with their support. As I drove to school in September on the first day back I had tears of happiness as I had been so excited for so long about this day and Janet, my fantastic assistant, and myself had spent all summer holiday sorting out the new classroom for the children. Unfortunately that day there was a flood and we had to begin all over again!

Twenty-six months after the onset on GBS we had a happy wedding when I married Terry followed by our hilarious honeymoon in Barcelona where we went to the wrong hotel and hopped on and off a big red bus. I continued to teach for a further sixteen years and retired at the age of 60, to spend more time with my two gorgeous little granddaughters. I haven't been able to play the guitar since the illness as I lost some strength in a couple of left fingers but at least I can pretend that I used to be a good musician! I can now do everything I want to do although I don't have

any intention of taking up long distance running! I do love dancing! Looking back maybe I should never have let on to anyone that I could iron! I have been very fortunate with my general health and I do have lots of energy. The GBS seems like a small blot on the landscape now and I would love to give hope and encouragement to anyone reading this who is struggling to be positive. I got better and have enjoyed some of the most amazing times since that day!

Anne Norland

GBS – Life Moves On

One year from GBS diagnosis

On 1 June 2015, at the age of 68, I was diagnosed with GBS. This followed a bout of food poisoning (campylobacter) a fortnight before. On 30 May I felt some weakness in my legs and by the morning of 1 June I had lost all use of arms, legs and hands. I was hospitalised for three months eventually coming home on September 8, just managing to walk a few steps and little else.

1 June 2016

I wake up this morning and, as most mornings, I stretch my legs and my body; tingling sensations, aches and pains course from my toes to my shoulders. After the initial discomforting sensations my body settles down again. I am reluctant to leave the comfort of my bed as I know that immediately I try to stand the challenges of the day stretch before me. However, I brace myself and totter to the bathroom with my walking frame which, in the house, I try only to use first thing in the morning whilst my legs are becoming acclimatized to the upright position. I have managed to develop strategies for washing, shaving, showering and other bathroom activities. These all seem to take significant amounts of time and energy, particularly if I have dropped the soap in the shower, and by the time I start to get dressed I am ready to sit on the side of the bed again.

I try to wear clothes that don't need buttons as these would present significant problems for my hands. It took me a long time to be able to tie my own shoelaces but now that is fairly routine, however occasionally the process of putting on shoes can have its problems. Sometimes I think that the aids that I use have a malevolent life of their own. I have a particularly tricky shoehorn, which when dropped, decides to bounce right under the bed causing me to grovel on hands and knees to retrieve it. Recovering from hands and knees position is also not easy.

I approach the stairs now with only minor trepidation. I am still going downstairs backwards as this seems to be the safest option although I know that I must attempt going down forwards in the very near future. Downstairs I walk without any aid, although even knowing the environment intimately, moving around is not without its dangers. Because the nerves are still growing (I hope!) one or other or both legs might collapse with no notice. This means that concentration levels at all times must be high.

I get my own breakfast but this means at least three journeys across the kitchen as I am only able to carry one or two items at a time. This is because of a combination of factors, strength and control of hands, and the need to concentrate specifically on each action. The brain must force the signals to the relevant parts of the body in order for them to respond effectively. I seemed to have developed a habit of weetabix, milk and honey as I can manage each of these individual items with little difficulty. I can also make myself a coffee provided I do not fill the kettle too full, so that I can lift it safely.

One year on sets me thinking. How would I have managed without the support of my wife, family and friends? Their support has been amazing. What was I doing just over a year ago? For my age I was fairly fit, I could cycle reasonable distances, I could walk with groups of friends, I had only just given up windsurfing because of the time commitment, I had recently being on a motorcycle trip to visit the World War I battlefields and I was planning a motorcycle tour to Scandinavia. (The motorbike had to go on eBay!) I managed the garden, grew vegetables and was a dab hand at the barbecue. After a layoff of over 50 years I had taken up fishing again, was really enjoying it and starting to teach my grandchildren some of the basics. But most significantly we were travelling rather than just holidaying. Our next big trip was to be New England, Hudson's Bay Canada and Florida. All of that finished on 1 June 2015! It seems now that I can do very little …. but on reflection there is much positivity.

> "I get my own breakfast but this means at least three journeys across the kitchen as I am only able to carry one or two items at a time."

In September, soon after coming out of hospital, I thought it would be good for me to go swimming. I have swum since I was about six and considered myself a fairly strong swimmer and not afraid of water. So with the help of my wife (who has been a fantastic support throughout) we went to the local pool. Fortunately there was a beach area so with the help of the lifeguards and a wheelchair I managed to get into the water. Clinging to the side I edged my way into enough depth to start swimming. I pushed myself forward intending to do a simple breast stroke width and to my horror, amazement and amusement, I sank straight to the bottom! I had no muscle memory of how to swim! I started again from the side practicing some strokes and after a couple of weeks I managed a width underwater, my arms still not being strong enough to raise my head above the water. Eight months on I can now do 20 lengths above the water with a combination of breast and backstroke. Yesterday I managed to climb the ladder out of the pool for the first time (with a little push from behind from my wife) rather than rolling out onto the side like a beached whale!

At the end of March I started driving again. The DVLA had never taken my license and while my case was investigated, had continually informed me that I still had a full legal license. I felt it wise to have some supervised driving in a car with dual controls. A sympathetic instructor took me out for a couple of hours and felt that I was quite competent. I have treated myself to an automatic car. This has made driving even easier and is becoming enjoyable again. Being able to get out and about on my own was a significant change to my life, liberating yet challenging. What would the terrain be like at my destination? How would I manage any activities when I got there? So forward planning became essential so that I could prepare myself for whatever I might be doing: shopping, sightseeing, short walks, restaurants, pubs, other people's houses. When out alone I still use the Delta frame as it provides me with security and enables me to walk greater distances.

We have now started going abroad again and tackling the challenges of airports, luggage and unknown terrain. So far with trips to Spain and Greece I have experienced only helpfulness by all airport staff, flight attendants and the general public. I have been swimming in the sea but this does mean that someone has to help me stand after crawling up the beach on hands and knees like some alien emerging from the depths. Boat trips have been challenging, but not impossible with the help of fellow travelers. Not being able to windsurf any more, I have just taken up sailing. My local sailing club has an Access boat which has been specifically adapted for disabled people. Once I am in it I can sail quite happily until I need to get out! I need a bit of help with this!

I have always been a very independent person so the greatest issue with which I have to contend is that of dependency. I need help with most domestic tasks, fishing, gardening, cooking and any activity which demands either strength, dexterity or even carrying things. This is my greatest frustration so I am continuing to explore activities which I might be able to do independently, whilst being enjoyable but also improving skills for normal living. In the near future I am looking at a tricycle instead of bicycle, I am exploring gliding lessons (independence once airborne!) and next summer will look at the possibility of a quad bike rather than a motorbike, manual dexterity permitting. Perhaps June 1 2017 will provide a more interesting reflection.

Gordon Wallace

My CIDP adventures

I have been invited to share with other gain4all readers my experience of CIDP over the past two years. I am in practice, as I recently gave an hour-long telephone interview to a modus researcher who wanted to know about my symptoms and response to IVIG treatment in minute detail. I know other CIDP patients are also taking part in this project, which benefits GAIN directly as well as all of us in the long run.

In a scenario that will be familiar to many of you, my first symptoms were a drastic slowing down in my mobility. Until then I had been a keen walker, including many long-distance trails (see photo), so it was very disturbing to find myself dropping behind the rest of our local walking group. Then I had a couple of unexplained falls. My hands were noticeably slippery, tingling and weak. My GP couldn't make sense of what was happening – which isn't surprising, as the average GP sees CIDP only once in their career, so rare is it. I won't bore you with the details, but eventually I collapsed and was admitted to our local General Hospital. Fortunately I was diagnosed by the consultant neurologist using an electromyogram, and admitted to the High Dependency Unit, with a catheter and feeding tube in place and an oxygen mask on standby in case my breathing packed up, and started on IVIG infusions, to which fortunately I quickly responded, and was discharged home after nearly three weeks.

That was in September 2014. Since then I have been through the usual CIDP cycles of getting stronger, peaking, and then deteriorating markedly. I have had another seven five-day courses of treatment, four of them as an in-patient and three at the Medical Day Centre. I am now booked in for further courses of treatment every eight weeks. So how would I assess the impact of CIDP on my life?

It has, of course, restricted me in ways that have been very frustrating and uncomfortable. My walking is now reduced to much shorter and easier routes, with the need to rest every few hundred yards. I have had to give up driving, and rely instead on our local bus service, offers from friends, and the occasional taxi. Holidays are problematic, and at present confined to day outings. I have had to come to terms with being substantially disabled, with all that implies.

On the other hand, I have had some very interesting experiences that I wouldn't have had if I had remained healthy - I had always wondered what being swallowed up by an MRI scanner was like, now I know! Moreover I have been in intimate care situations with people I would never have met, hospital staff and fellow patients, and (most of) these have been very rewarding. And as neurological conditions go, CIDP is at least treatable and not progressive for most people, compared to Parkinson's, MS etc. And the treatment itself is not only painless, but rather relaxing (see photo).

In the end, everyone will respond differently to the challenges of CIDP. I have the advantages of a generally optimistic temperament (I'm a 'glass half full' man); a caring wife and family, and kind supportive friends; a Christian faith; excellent hospital and community services; hobbies and a range of (mostly) local activities I can still enjoy, particularly swimming and Tai Chi, which I find very beneficial. Would I rather that I had never been struck down by CIDP? Of course. But can I continue to enjoy life and keep going? The answer, so far at least, is an emphatic yes.

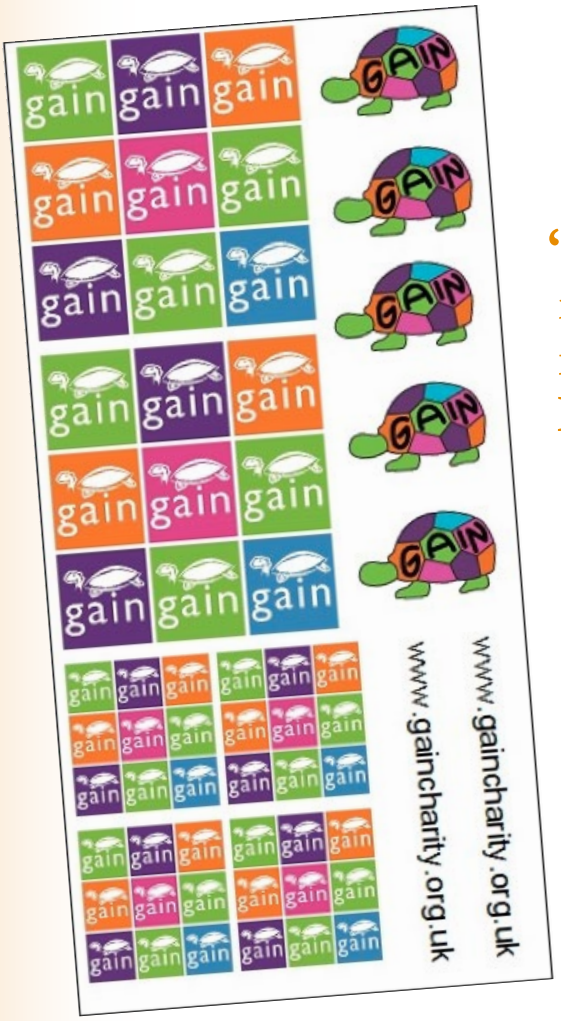
Don Archer

Fun and Funky

Check out the new range of GAIN gift ideas.

Fancy a tattoo? Or a new pin badge? Maybe a button badge?
Well here they are …

"The pin badges are flying off the shelf as members snap up the new design"



"We hope to extend the range so look out for the new items on our website and on Facebook"

GETTING BETTER SLOWLY

AN INSPIRING STORY OF ILLNESS AND RECOVERY

Adam Pownall woke up to find his body was slowly shutting down. Unable to walk, talk or blink and nobody knew why….

When Guillain-Barré syndrome affected Adam it caused full paralysis with days. Getting Better Slowly tells the story of his illness through new writing, sound and movement. Funny, moving and honest, Adam's journey from diagnosis to rehabilitation and beyond – including months relearning how to walk and talk – invites audiences to consider how they would deal with an unexpected illness or accident, and explores how it feels when your closest relationship is with the illness that is holding you back

www.gettingbetterslowly.com

the place to book your tickets and see the latest news

Performed by
Adam Pownall
& Kitty Randle

Creative Producer
Adam Pownall

Director
Tilly Branson

Movement Director
Marc Brew

Writer
Nick Wood

Associate Dramaturg
Luca Rutherford

Music
Poetical Machines

Designer
Kate Unwin

Tour dates and venues

Lincoln Drill Hall - 22 & 23 Sep
Barnsley Civic - 1 Oct
New Diorama, London - 2 & 3 Oct
South Holland Centre, Spalding - 12 Oct
Old Library, Mansfield - 14 & 15 Oct
Attenborough Arts, Leicester - 22 Oct
ARC, Stockton - 3 Nov
Square Chapel, Halifax - 6 Nov
Riverhead Theatre, Louth -15 Nov
Guildhall, Grantham - 16 Nov
Stamford Arts Centre - 17 Nov
Deda, Derby - 1 Dec
Nottingham Lakeside Arts - 2 Dec
CAST, Doncaster - 15 Feb
Harrogate Theatre - 17 Feb
Slung Low Hub, Leeds - 19 Feb

NEWS from around the regions

Lancashire & Cumbria

After meetings affected by floods and snow it was good to welcome the sunshine for the quarterly Lancashire & Cumbria Branch meeting on 18 June, which appropriately was a Plant Sale combined with a potting demonstration from local gardening expert and poet, Tim Smith. Tim's talk was full of gardening tips and observations on life as he set about constructing two beautiful pots, each one to a carefully chosen colour scheme using, to our surprise, mostly perennial plants. The talk was enjoyed by all present and the two pots, generously donated to the raffle, were swiftly taken by the first two tickets out of the draw.

We then moved on to our regular Sufferers' & Supporters' Forum when we exchange experiences, questions, and tips on living with GBS & CIDP. This included discussion of the benefits of tonic water in countering cramp and different treatment options for CIDP. Finally we tucked into beautiful strawberry scones (thank you Rosie), cakes and tea as we completed the draws for the 100 Club and raffle, and spent our final pennies on plants and preserves.

Future meetings are on 24 September (talk from one of our members on the Prevention of Radicalisation of Children) and 3 December (Christmas Party) all at Bilsborrow Village Hall on the A6 north of Preston, commencing at 2.00pm

Yorkshire

The next meeting will be on Sunday 16 October at the Betty Boothroyd Centre, Dewsbury Hospital commencing at 2.00pm

South West England

The next meeting will be on 15 October in Dorchester with guest speaker Lisa Shirley (physiotherapist).

2016 Christmas Cards

1. Santas New Hat (with foil)
81 x 200mm
£4.25 for 10 cards

2. Home in Time for Christmas
121 x 121mm
£3.75 for 10 cards

3. Robin in the Snow
137 x 137mm
£3.95 for 10 cards

4. Frosty Tree (with flitter)
81 x 200mm
£4.25 for 10 cards

6. Floral Wreath (with silver foil)
121 x 121mm
£3.75 for 10 cards

7. Choir Boys
137 x 137mm
£3.95 for 10 cards

The Greeting inside these cards reads: *With all good wishes for Christmas and the New Year*

5. Stained Glass Bethlehem
137 x 137mm
£3.95 for 10 cards

9. Postie (with GAIN details on van)
137 x 137mm
£3.95 for 10 cards

10. Bobbing Robins (with red foil)
200 x 81mm
£4.25 for 10 cards

8. Sheep at Sunset
137 x 137mm
£3.95 for 10 cards

A variety of 20 cards from the GAIN selection

11. Variety Pack
Various sizes
£7.45 for 20 cards

12. Gift Wrap
6 sheets & 12 tags
£2.95

2016 Christmas Card Order Form

Please send this order form together with payment to: Guillain-Barré & Associated Inflammatory Neuropathies (GAIN), Woodholme House, Station Road, Heckington, Sleaford, Lincolnshire NG34 9JH

(Charity number 1154843 & SCO39900)

Guillain-Barré & Associated Inflammatory Neuropathies

Card Ref.	Title	Quantity per pack	Price per Pack £	Number of packs	Total price per line £
1	Santas New Hat (with foil)	10	£4.25		
2	Home in Time for Christmas	10	£3.75		
3	Robin in the Snow	10	£3.95		
4	Frosty Tree (with flitter)	10	£4.25		
5	Stained Glass Bethlehem	10	£3.95		
6	Floral Wreath (with silver foil)	10	£3.75		
7	Choir Boys	10	£3.95		
8	Sheep at Sunset	10	£3.95		
9	Postie (with GAIN details on van)	10	£3.95		
10	Bobbing Robins (with red foil)	10	£4.25		
11	Variety Pack	20	£7.45		
12	Gift Wrap & Tags	6 sheets	£2.95		
				Subtotal	
				Post and packaging	
				Donation – Thank you	
				Total price £	

For delivery outside of the UK, please contact us for a price
Tel: +44 1529 469910 or email office@gaincharity.org.uk

Postage and Packaging UK	**1 item - £0.94**	**2 or more items – £2.67**

We hold a large stock of cards, but some designs sell out early. Should this occur, please select box and tick below to advise what should be done with balance of money.

☐ Send alternative cards, similarly priced ☐ Donation to us ☐ Refund

Boost your donation by 25p of Gift Aid for every £1 you donate. Just complete the boxes below.

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer; don't give your work address if you are Gift Aiding your donation.

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Print name _____ Signature _____ Date _____

Payment by cheque

Cheque enclosed for £ _____ (Sterling only) payable to: **GAIN**

Delivery details
Name
Address
Post code Telephone number

Cards and other logo items are also available through the GAIN online shop: **www.gaincharity.org.uk**

Useful links

Age UK
http://www.ageuk.org.uk/

Helpline 0800 169 6565

Information, advice and support for older people

Carers Trust
http://www.carers.org/

Tel: 0844 800 4361

Support and services for carers

Citizens Advice Bureau
http://www.citizensadvice.org.uk/

Tel. (Wales) 08444 77 20 20
Tel. (England) 08444 111 444

Free independent and confidential advice including fact sheets, sample letters and budget calculator

CAB self-help website
http://www.adviceguide.org.uk/

Cochrane Library
http://thecochranelibrary.com/

Independent high quality evidence for health care decision making

Department Health IVIg
http://www.ivig.nhs.uk/

A resource to healthcare providers to understand the Demand Management Programme for Immunoglobulin and access guidance and materials to ensure its effective implementation

Direct Gov
https://www.gov.uk/

Information on benefits, DVLA etc

Disabled Living Foundation
http://www.dlf.org.uk

Helpline 0300 999 0004

Impartial advice, information and training on daily living aids

Expert Patients Programme
http://www.expertpatients.co.uk

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

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

Euan's Guide
http://www.euansguide.com/about-us/

Listings and review website to help disabled people find accessible venues

Listening Books
www.listening-books.org.uk

A service for those whose illness or disability makes it difficult or impossible to hold or concentrate on reading a book

Money Advice Service
https://www.moneyadviceservice.org.uk/en/

Not for profit government organisation created solely to help people with their finances

Neuro News
http://www.neuro-news.co.uk

Community hub for information on neurological conditions

Neurological Alliance
http://www.neural.org.uk/

The only collective voice for more than 70 national and regional organisations working together to make life better for 10 million children, young people and adults in England with a neurological condition

NHS Complaints Advocacy
http://nhscomplaintsadvocacy.org

The NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about a National Health Service (NHS).

Pubmed
http://www.ncbi.nlm.nih.gov/pubmed/

Citations for biomedical literature from MEDLINE, life science journals, and online books

Rare Disease UK
http://www.raredisease.org.uk/documents/patient-experiences-2015.pdf?mc_cid=fe312c92e6&mc_eid=e173e4b5e2

The National Alliance for people with rare diseases & all who support them

Scope/DIAL
http://www.scope.org.uk/dial

Local disability information and advice

Turn2us
http://www.turn2us.org.uk/

Helping people to access welfare benefits, charitable grants and other financial help

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