

gain4all

For people affected by GBS, CIDP & the associated variants

Guillain-Barré & Associated
Inflammatory Neuropathies
gain4all issue 14 / Spring 2019



Glennys Sanders
House

Official opening of
Glennys Sanders House
Pages 20-21

YOUR STORIES

Life Interrupted
Full Circle – Volunteering for GAIN
A Plan Postponed
My Much Younger Sister
A Father's Day that's hard to forget

ALSO INSIDE

May is GBS/CIDP Awareness Month!
New documentary to shine a light on GBS
Free Will-writing service launched
Avoiding falls through exercise
Eat your way to a healthier you



Getting Better Slowly



Dedicated to helping people affected by
Guillain-Barré syndrome, CIDP & the
Associated Inflammatory Neuropathies



Supporting you every step of the way
www.gaincharity.org.uk

Guillain-Barré syndrome is a rare autoimmune condition affecting the peripheral nervous system which causes rapid, ascending paralysis. Around 80% of people with **GBS** will make a good recovery, usually over many months, but between 5-10% of people will not survive, and another 10-15% may be left with severe disability.

Chronic variants such as **CIDP** are similar but tend to progress more gradually and require ongoing treatment, sometimes for life.

Approximately 1-2 people per 100,000 are diagnosed with GBS each year, and a further 1-2 per 200,000 with CIDP.

Getting a diagnosis of Guillain-Barré syndrome, CIDP or one of the variants can be an isolating experience, but it doesn't have to be. Get in touch and find out how we can help.

Visit our website or contact us:

Office **01529 469910** (Mon-Fri 9am-3pm)

Helpline **0800 374803** (UK)

1800 806152 (RoI)

Email **office@gaincharity.org.uk**

Find us on social media   

GAIN is a registered charity, number 1154843 & SCO39900



Getting Better Slowly

Do you have a story you would like to share with our readers? Please email submissions for the next issue before **31st August 2019** to:

gill.ellis@gaincharity.org.uk

Preferred format: Word document
(text only - photographs to be emailed as separate files in jpeg or png format)

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(<https://www.instagram.com/gaincharity/>)

Guillain-Barré & Associated Inflammatory Neuropathies is a registered charity, numbers 1154843 (England and Wales) & SCO39900 (Scotland)

The views expressed in this publication should not necessarily be taken as the policy of Guillain-Barré & Associated Inflammatory Neuropathies (GAIN). Whilst every care is taken to provide accurate information, neither GAIN, the Trustee board, the editor nor the contributors undertake any liability for any errors or omission.

CONTENTS

Your Stories

Life interrupted (Jodie Granger)	10
Full circle (Jon Shelton)	16
A plan postponed (Caroline Wilson)	18
My much younger sister (Ann Pennington)	31
A Father's Day that's hard to forget (Mike Plumb)	32

News & Information

Free Will-writing service launched	7
Save £££s with a Prescription Prepayment Certificate	8
Are you due a reduction in Council Tax?	9
Glennys Sanders House official opening	20
'Wonderful' fee-free fundraising platform	35

Get Involved

New documentary about GBS & CIDP	4
New survey under development at Lincoln University	5
May is GBS / CIDP awareness month	6
Eat Crisps for Charity!	14
Fundraising Hall of Fame	27

Focus on Health & Wellbeing

Effectiveness of exercise to prevent falls	22
Get fit for free	23
Eat your way to a healthier you	24
What's in a colour?	25

Also inside

Call in Time – AGEUK telephone befriending service	8
Regional round-up	36
Letters page	28
Other organisations	39



Throw a tea party to raise awareness of GBS & CIDP

See page 6

New documentary to throw a spotlight on Guillain-Barré syndrome & CIDP



BAFTA-nominated documentary maker Xavier Alford is looking for people to get involved in an exciting new project to raise the profile of these rare auto-immune conditions.

My name is Xavier Alford, I'm a BAFTA-nominated documentary director and I'm currently making a documentary feature film about the neurological illness, Guillain-Barré syndrome.

I was diagnosed with CIDP (a chronic form of the syndrome) over 8 years ago and feel very strongly about the lack of public understanding or awareness of the condition and other similar neurological diseases. I have recently been commissioned by the BBC to make a feature length documentary about the illness that I hope will help raise public awareness.

I am dedicated to making this film in order to give those with neurological illnesses a platform to share their stories and experiences with a wider audience. I have been researching this project for over a year with the full support of several leading consultant neurologists and the national charity Guillain-Barré and Associated Inflammatory Neuropathies (GAIN) and have recently secured financial backing from both the BBC and the BFI (British Film Institute).

One element of the film is to chart my own experience of day-to-day life with the illness as my physical condition is deteriorating and beginning to affect my ability to use cameras and film documentaries, something I have done all my life.

Locked in

Another key component of the film would be to interweave stories of other people who are at various stages of recovery from acute GBS. But I feel the most important aspect of the illness, and the one that is the most challenging to cover, is the state of being locked-in.

We do of course understand that the early stages of acute GBS is an incredibly stressful time, for the

individuals themselves and those closest to them. However, we believe in order to raise awareness, and truly reflect the reality of the condition in an honest and sympathetic way, it is important we make every effort to find individuals who are locked in and give them the opportunity to have a voice and to tell their story.

We appreciate the complications around consent regarding patients who are currently 'locked-in' and would love the opportunity to explain how we could work through these issues with the family during the initial stage. If you are at all interested in finding out more about this project, we'd love to have a chat.

Any conversations will of course be in the strictest confidence and with absolutely no commitment to being involved in the final film.

We can also send through our 'Ways of Working' document with more details about our filming protocols, editorial guidelines and duty of care towards contributors.

As someone living with a chronic neurological condition, I am passionate about this project and hope it can offer a strong voice to those affected by this illness, whether directly or indirectly, including partners, carers or family members.

Xavier Alford

www.marblefilms.co.uk

If you think you might like to get involved in this project, please contact us at GAIN Head Office and we will forward your details to Xavier

Email: office@gaincharity.org.uk

Tel: 01529 469910 (weekdays 9am to 3pm)



New survey under development at the University of Lincoln

A team at Lincoln University is exploring the experiences of people affected by Guillain-Barré syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). They are looking at the care and treatment of people living with these conditions in the UK and Republic of Ireland, and how they can return to their lives following discharge from hospital, functioning as well as possible from a physical, psychological and social perspective.

This will be achieved using a series of studies:

1. A systematic review of the published research on the experiences and views of people living after GBS or with CIDP
2. An interview study exploring experiences of the illness, its care and return to function in more depth
3. A survey to gather information more widely from people with these conditions

All parts of the study will be linked, each informing the next, and will be brought together in a report. Together they will provide robust and credible evidence needed by the charity to provide support and advice to people with GBS and CIDP to help them return to good function. It will also provide valuable information for patients, their relatives, health

professionals, commissioners of services and academics with an interest in this field.

The first two stages have been completed already, with the University receiving a fantastic response from people wanting to get involved.

Further information about the final survey stage will be published on the GAIN website and social media platforms once it becomes available.

We will also be rolling out the survey directly to members of GAIN; if you are interested, please make sure we have your name and email address, along with permission to email you about trials and studies.

Count me in!

If you would like to hear about opportunities to get involved in studies and trials, then please let us know here at GAIN

Email your details to:
office@gaincharity.org.uk

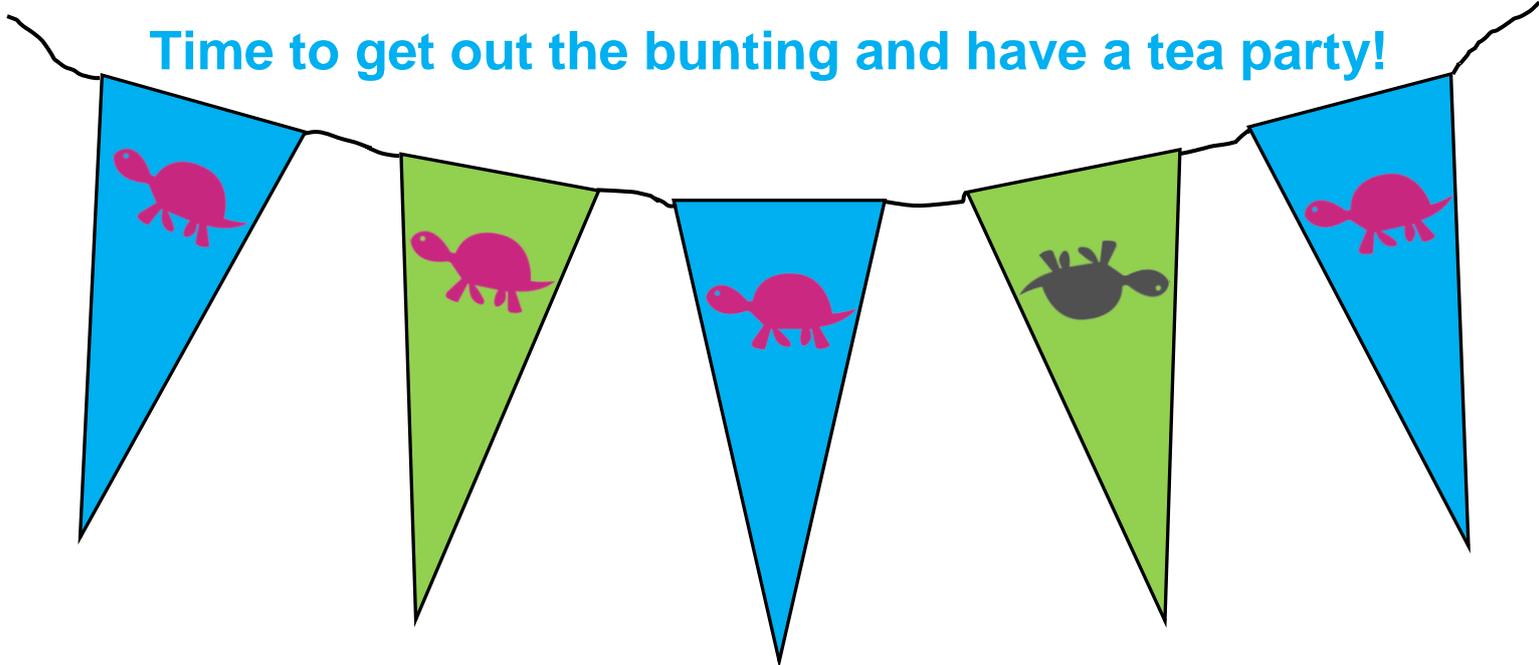
Subject line:
Studies and Trials

Include the following information:

Name
Address
Phone number
Date of birth
Diagnosis
Date of diagnosis

May is Guillain-Barré syndrome awareness month!

Time to get out the bunting and have a tea party!



During the month of May, we are asking our supporters to help raise awareness of GBS & CIDP by hosting a tea party, inviting your friends, family, neighbours, colleagues and anyone else you can think of to join in.

If you would like to take part, please get in touch with your name and address, and we will send you a kit containing some information flyers, a small collection box for donations, a tortoise-shaped cookie cutter and a dozen edible cupcake toppers to help you get started. Templates for bunting and customisable invitations and posters will be available via email or the website.



Email enquiries to:
office@gaincharity.org.uk
subject line Tea Party!

Telephone **01529 469910**
office hours, Mon to Fri



Or why not join us for a cream tea in our new office?

To celebrate the end of GBS/CIDP Awareness Month, we are inviting our supporters to a cream tea, and would love you to come along if you're in the area.

2-4pm on Friday 31st May 2019

**Glennys Sanders House, Pride Parkway,
Sleaford, NG34 8GL (opposite The Reservation)**

Please let us know if you are planning to join us, so we can make sure we have enough scones and cake!

As well as getting together over a cuppa and a cake, we would love our supporters to use the GBS/CIDP Awareness Month as a springboard for raising awareness in their local community. One way to do this is to take our information to your local GP surgery, hospital, Citizens Advice office, etc so that people can be signposted to the charity to access support and information when they need it most.

Please phone or email us to request a pack containing posters and leaflets.

GAIN is delighted to launch a new FREE Will-writing service in partnership with McClure Solicitors



Many charities receive the bulk of their income from legacies (gifts left in people's Wills) from supporters who like to remember them. After providing for family and friends, leaving a legacy in your Will to GAIN is a tremendous and thoughtful way of supporting our work and is **exempt from inheritance tax**.

If you would like to remember GAIN and have not yet made a Will, it is advisable to see a solicitor or other professional and give your instructions. If you have already made a Will, the simplest method of amending it is to write a codicil, sign it in the presence of witnesses and keep it safe with your existing Will.

GAIN has partnered with McClure Solicitors to provide a free Will-writing service for our members, friends, volunteers and staff who want to write, update or review their Will. This service is FREE to both you and to GAIN.

McClure Solicitors will write you a free Will. They also offer a free Will Review service, a discounted Lasting Power of Attorney and a full price Family Protection Trust. They are able to offer free Wills because over 50% of their free Will clients choose to use them for another paid for service. You will be asked to consider making a donation for a charity of your choice, which we hope is GAIN.

Founded in 1853 McClure Solicitors is a national company with offices in Edinburgh, Glasgow, Aberdeen, Inverclyde, Cardiff, London, Birmingham, Exeter, Leeds, Liverpool, Newcastle, Plymouth, Southport and Truro. They do not yet operate in Northern Ireland. McClure will consider a home visit if you are unable to travel to their offices. That's also free.

At the appointment to make your Will, you will be asked if you would like to make a charitable donation in return for the service. You are under no obligation to do so, but if you do, McClure will send your donation on to the charity with a Gift Aid declaration where applicable.

There is no obligation to leave a gift to GAIN when using the Free Will Service, but we would be very grateful if you consider it. A gift in a Will, no matter how small, would help us to provide the practical, emotional and financial help that people affected by GBS, CIDP and the associated inflammatory neuropathies rely on.

To arrange your consultation, call McClure Solicitors on Freephone 0800 852 1999. Please mention GAIN.

As we rely entirely on voluntary donations, legacies are vital to us. Thank you.

Call in Time



Would you, or someone you know love to talk to someone every week?

Age UK now offer a free weekly friendship call for the over 60s.

What is Call in Time?

Not having someone to talk to regularly can be lonely and isolating, particularly if you're used to sharing your home and time with others. A friendly, weekly, 30-minute chat on the phone can make all the difference.

Call in Time is a free telephone befriending service for matching Age UK volunteers with older people.

While we're waiting to find a suitable match, we carry out regular, short Good Day Calls to bridge the time gap.

How does Call in Time work?

Call in Time follows a straightforward process.

1. **You sign up** and register interest.
2. **We assess your profile** (or the older person you're referring)
3. **We match up** with a suitable volunteer
4. **We then connect** the volunteer to begin weekly calls

How to sign up

Call the team on 0800 434 6105

For further information, visit www.ageuk.org.uk



Do you pay for two or more prescription items each month? You could save over £100 each year with a Prescription Prepayment Certificate (PPC).

If you know you'll have to pay for a lot of NHS prescriptions, it may be cheaper to buy a PPC – effectively a prescription "season ticket".

A PPC covers all your NHS prescriptions, including NHS dental prescriptions, no matter how many items you need.

A 12-month PPC costs £104.00 and will save you money if you need more than 11 prescribed items in a year

How much can I save?

If you need:

- 2 items each month
Save £112 with a 12-month PPC
- 3 items each month
Save £220 with a 12-month PPC
- 4 items each month
Save £328 with a 12-month PPC

There are several payment options available. You can even spread the cost of a 12-month PPC with 10 monthly direct debit instalments of £10.40.

How to apply for a PPC

(check whether you are entitled to free prescriptions first)

It's quickest to buy your PPC online. The PPC will start from the day you submit your application, unless you request a different start date, but the start date must be within 1 month before or after the date of your application.

If you prefer talking to someone, you can call the PPC order line on 0300 330 1341. Again, your certificate is valid from the day you make the phone call, unless you request otherwise.

For further information, visit www.nhs.uk and search for PPC

Could you be due a reduction in council tax?



Council tax is a system of local taxation collected by local authorities. It is a tax on domestic property. Some property is exempt from council tax. Some people do not have to pay council tax and some people get a discount.

Properties exempt from council tax

Some property is exempt from council tax altogether. It may be exempt for only a short period, for example, six months, or indefinitely.

Properties which may be exempt include:

- property which has been legally re-possessed by a mortgage lender
- property **unoccupied** because the person who lived there now lives elsewhere because they need to be cared for, for example, **in hospital, in a care home** or with relatives
- property which is **unoccupied** because the person who lived there has **gone to care for someone else**
- a property where all the people who live in it are aged under 18
- property which is occupied only by people with severe mental impairment
- a self-contained 'granny flat' where the person who lives in it is a dependent relative of the owner of the main property.

Reduction scheme for disabled people

If there is someone (adult or child) living in a household who is substantially and permanently disabled, the council tax bill for the property may be reduced. The reduction is made by charging council tax on a lower valuation band than the one the property is in.

To claim a reduction, you must show that a disabled person lives in the property, and that the property has at least one of the following:

- an extra kitchen or bathroom to meet the needs of a disabled person
- any other room (except a toilet) which is mainly used by a disabled person to meet their needs
- enough indoor space for a disabled person to use their wheelchair.

Discounts

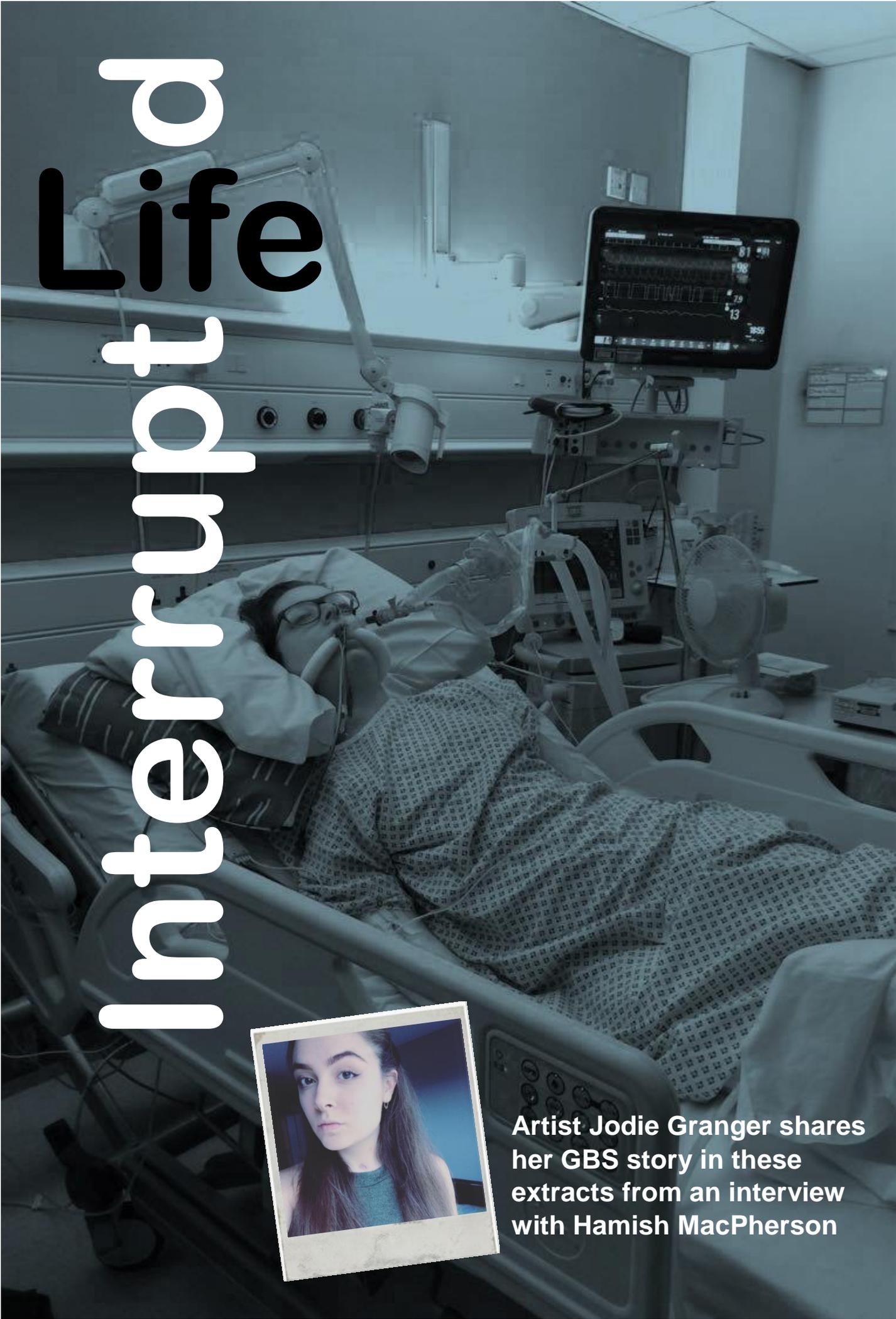
If only one adult lives in a property, they will get a 25 per cent discount on the council tax bill. When working out how many people live in a property, some people are not counted. These are called **disregarded people**.

Disregarded status includes:

- aged 17 or under
- 'severely mentally impaired'
- full-time students on a qualifying course of education / young person on an apprenticeship
- a **long-term hospital patient** or care home resident

If you think you may be paying too much council tax, ask for help from Citizens Advice Bureau. Find your local one here: www.citizensadvice.org.uk

Life Interrupted



Artist Jodie Granger shares her GBS story in these extracts from an interview with Hamish MacPherson

Jodie Granger was diagnosed with Guillain-Barré syndrome in February 2017, interrupting her second year at university. Here, she talks to Hamish MacPherson about the weeks following diagnosis.

JG It all kind of started randomly on a Monday. The very first thing that I noticed was when I washed my hands it felt spiky. I remember having a bit of hypersensitivity to the temperature in the water and if it was particularly cold it would be, like, spiky so I was a bit like 'ooh that's a bit weird, maybe I'm just having a weird moment'. So it was my hands and also in and around my mouth and then my feet started feeling funny as well, and when I would get into bed the touch of the sheets felt spiky and weird like a flash of cold or something.

So on the Tuesday I went to the doctors and I was like 'this feels weird'. They checked my reflexes and they had no idea. I went home and hoped it would be better the next day but the next day that weird change in sensation had spread all over my body so I realised there was definitely something wrong going on. I found it difficult to get out of bed or to start walking so I then went straight to King's College Hospital to the walk-in blood test centre.

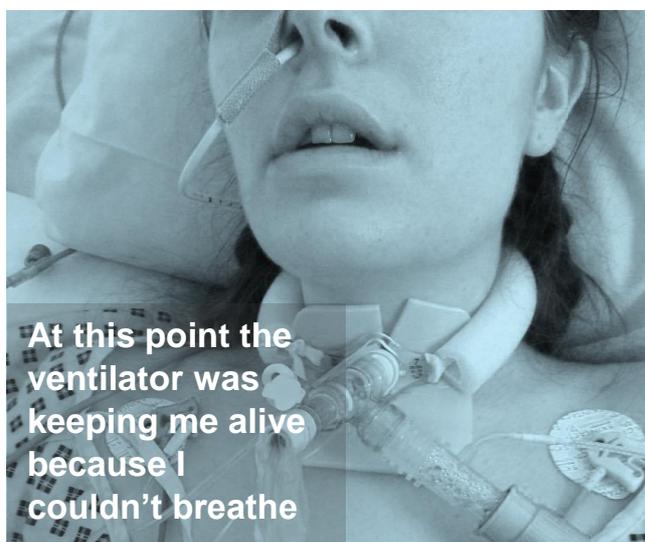
I kind of panicked and they brought me to A&E and I stayed there for a bit and then had my blood tests and it all came back fine so I was sent home again and then the next day I didn't want to get out of bed and I was throwing up. I was finding it difficult to get out of bed and go to the toilet. I remember using the wall to try and get there and then I was on the phone to my mum and she said I sounded slurred so she was worried. She came up to London that evening was going to take me home until I got better but I got worse and the next day I really, really didn't want to get out of bed because I couldn't.

Pins and needles was another thing that came along with this, especially from the extremities up, from my feet and hands up and in and around my mouth outwards. So at this point I rang the doctors and they said go to A&E because you can't walk very well and that was that. And then at 3am I was finally put onto a ward.

I spent a few days there getting gradually worse; GBS had been mentioned quite quickly and the doctor who came was a neurological consultant. She knew her stuff, which was really reassuring because we were all freaking out.

One thing Dr Norwood could say was it wasn't anything to do with my brain or spine. It was the connections to muscles that were being damaged. It was an auto immune response, because it was my own body that was attacking the myelin sheath. I learnt about this in Biology; your nerves have a myelin sheath which insulates the nerves and that was being damaged and without that insulation the messages couldn't travel. If you Google it, it will explain it with diagrams; it's really interesting.

So, the connections to my muscles weren't happening. I was intubated and at this point the ventilator was keeping me alive because I couldn't breathe and it was breathing for me - pushing air into the lungs and taking it out.



At this point the ventilator was keeping me alive because I couldn't breathe

Once I had the tracheostomy, I couldn't talk as well as not being able to move. The way I was having to communicate was with a spell chart board, spelling out words letter by letter. They would have to hold it...my eyelids wouldn't close when I slept either so I had to have droplets to protect them...really thick coating on my eyes so my eyesight was really blurry...it was so hard to communicate this.

HM *What would you be communicating about?*

JG It would be in what way am I uncomfortable, what I need them to do. It felt like my entire body was burning. I would say if I needed changing positions or something because I'd still feel uncomfortable all the time and if you're bed-bound they need to turn you every four hours and that was quite a painful experience. And the more I was starting to heal the more pain I would experience like stiffness or bruising pain so when they would move me, it would get more and more uncomfortable and painful but I just had to explain it by spelling it out.

When you have a tracheostomy there's lots of focus on mouth care. I would have massive amounts of saliva being produced so one of the things I'd spell out would be 'suction' and they would have to suction my mouth a lot.

And I had mouth thrush, I had pneumonia. They would talk about managing your secretions...so the reason why I had pneumonia in my chest was because there was a lot of mucus not being cleared because you can't cough yourself, you have to spell out 'cough.' With the trachey there's a little tubey thing, they push it down your trachey - it sounds horrible but it became a very normal thing - so they put a little tube down your trachey which irritates it and then you involuntarily cough and they would suck up the mucus.

“I felt like there was always something in my mouth like a hair when there wasn't”

But then also my mouth would be unbearably dry, my lips would be chapped all the time and no amount of lip balm could fix that so that would be irritating.

And the weird thing about what was happening with the senses and my mouth was that I felt like there was always something in my mouth like a hair or something when there wasn't. I was obsessed. That would be another thing I would try to communicate about I'd be like 'I've got something in my mouth, there's something in my face' when there wasn't at all. It was something that I felt as the sensation was starting to come back - this is what they explained - I would just have every weird feeling you could possibly imagine with temperature, touch, all that pins and needles weirdness, I would experience that everywhere.

HM *Was the care team consistent over time?*

JG Yeah. I had occupational therapists, physical therapists, speech and language therapists, who were great - each of them would visit me once a day. The nurses are on a rota so you get one nurse to each patient in the ICU, one during the day and then they swap for the night nurse so you're constantly under care. I would have got to know the team and would have had the same nurse more than once so in that way it was consistent but the anxiousness levels...especially during the night when my parents weren't there to help me communicate.

You had to be really determined to do physio. To start off with I couldn't do a lot of physio, I couldn't move very much but when I regained...the first

physio I had was they support my elbow and my hand and moved it upwards so it's just this flexion, they would I support my wrist here and I would kind of try and lift. To start off with I couldn't really lift my arm but I'd be trying to with all my might. I'd be really intensely looking at what I was trying to move. It was super weird - imagine having no muscles - it felt like I had no muscles to move it.



To begin with I couldn't really move my head or neck but at this point I could probably move my neck a little bit side to side, that would be something that the physios would say to practice. I couldn't properly move my mouth very well. If I tried to mouth something at this point it wouldn't have come across. My right side came back first and it was followed by my left side so I was lopsided for a while.

There's so many areas of the body that I had to work out how to gain access to. There was the arm stuff, the communication, I had to have several enemas because I couldn't go. So the top half of the body was coming back first and the lower half was following, taking longer.

HM *Where are we in terms of time?*

JG I'd say this was the second or third week. I was in ICU for a total of five weeks so around the third week. Eventually they started doing similar exercises with my legs. Holding my ankles, trying to flex my ankle back and forth and push away the physio. They'd have their hand by my foot going 'push push push' and I'd be trying my damndest.

All this time I would be monitored every day, for my progress. They would be like 'can you wiggle your toes?'. And I wouldn't be able to see it so I'd be 'am I doing it? I don't know.' They'd say 'it was just a flicker' but each time they would ask I would be able to do it a bit more and that's when they could start working with my feet.

And as this was progressing, communication-wise I'm getting better because I can have the spell chart on my lap and if I'm sat up on the bed I could point with my finger so things were getting better communication-wise. And then I was practicing spelling each letter on my leg.

HM *Drawing the shape on your leg?*

JG Yes drawing the shape on my leg. That was quite good physio on dexterity as well. I was still frustrated at the pace of things, I would have thought 'my legs aren't getting better, my arms might be getting a bit better but I'm not going to be able to walk in two or three months from now. Maybe if I'm lucky'.

And then at one point I was lying on my side and I had a visitor and I suddenly tried to move my legs and then they sort of went like that [demonstrates flexing at the knee] and when that happened, we were all quite shocked. We were like 'uh!' It was pretty amazing. And then around that time they would have been sitting me out in the chair, trying to get my body more used to being upright because I was so flat most of the time. You have to regain your confidence, so you can bear being upright again.

And then eventually my swallowing sensation was coming back so then I was able to drink water and eat so that was really good and I was getting stronger and stronger and then the next stage of physiotherapy would have been something like sitting on the edge of the bed so then it was testing core muscles and butt muscles and lifting my head.



Also, we started doing reaching as high as possible. I couldn't do it, and there were strained muscles, but obviously you had to engage with it because otherwise I don't know how I would have got better or regained my strength.

And the ventilator, I changed to something called Optiflow which was just a little bit more oxygen support rather than the ventilator - what that does



Getting a lot stronger – standing up for the first time

is push air into your lungs and take it out again, but with the Optiflow it was me myself breathing through this hole. It's really weird when I'm talking about it because you can't imagine breathing out of anything but your mouth. I would be actively noticing that I was able to move up and down and take deeper breaths and they would be saying 'practice this' and the less support I was on the harder work it was and the more out of breath I got so that was a part of the physio.

At this point I am getting a lot stronger and then there was something called a Sara Steady. You sit on the edge of the bed and there were two handles, you grab them, you step up onto it and then you have to try and pull yourself up like that. They would support you and push you up as well but you had to push down your legs and pull yourself up so that was the first time I'd been standing up.

One thing that was really amazing, I was finally able to use a wheelchair and I could be wheeled out of the hospital, my parents could take me. I'd go out every day. That was quite an emotional thing because I hadn't been outside for six or seven weeks.

Jodie's interview is available to read in full at www.gaincharity.org.uk. Our thanks go to Jodie Granger and to Hamish MacPherson for allowing us to print these extracts, originally published in 'Still Life' magazine.

All photographs courtesy of Jodie Granger

Eat crisps for charity!



GAIN has signed up as a collection point for recycling crisp packets (all brands, not just Walkers)

This scheme is a partnership between TerraCycle and Walkers and allows people to recycle their crisp packets and at the same time raise money for charity

How it works

- Buy your favourite crisps
- Eat your favourite crisps
- Encourage crisp-eating amongst friends and family
- Collect your empty crisp packets and when you have a big pile, post or take along to;

GAIN
Glennys Sanders House
Pride Parkway
Sleaford NG34 8GL

Please eat crisps responsibly!

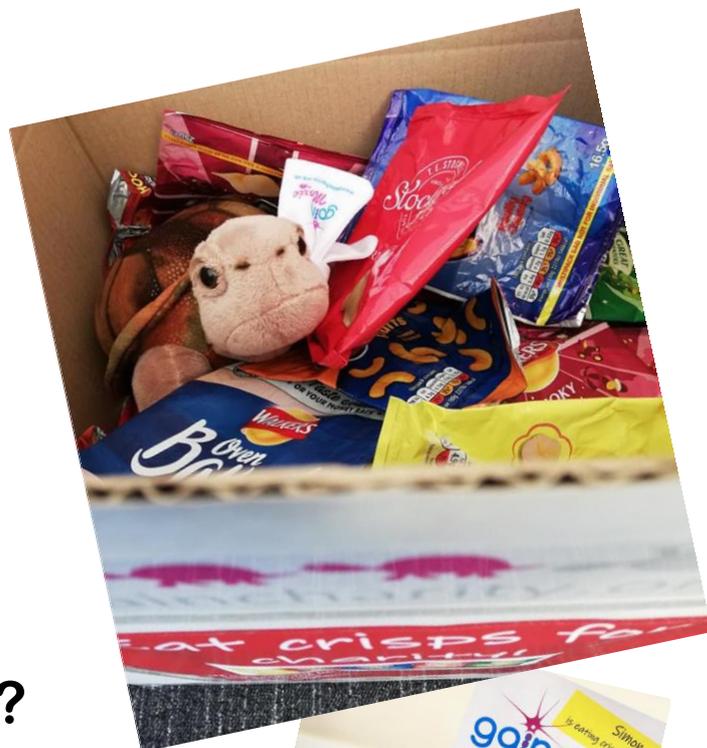
 Dedicated to helping people affected by GBS, CIDP & the associated neuropathies

www.gaincharity.org.uk

Registered charity nos
1154843 & SCO39900

Eat Crisps for Charity

(& raise funds and
awareness for GAIN)



How does that work then?

If your local council has a long list of things 'Thou Shalt Not Put in The Recycling Bin' you might be thinking, 'but crisp packets can't be recycled!'

TerraCycle UK have several free recycling schemes to allow people to recycle materials that would otherwise go to landfill or for incineration.

This scheme, in partnership with Walkers Crisps allows people not only to recycle their crisp packets, but to raise money for charity at the same time!

GAIN has signed up to the scheme as a collection point, so all you have to do is send your empties to us. Collect empty crisp packets (ALL BRANDS ACCEPTED), and when you have a nice big pile, send them to us here at Head Office.

1. Pack 70-80 empty crisp packets (flat, not folded or scrunched), in a medium-sized zip lock bag
2. Almost close the bag, leaving about 2cm open at the end.
3. Roll the bag from the bottom upwards to squeeze out every bit of air, and then fully close the bag. This essentially vacuum-packs your crisp bags, so they fit within the maximum dimensions of a large letter (35.3cm x 25cm x 2.5cm).
4. Pop your zip lock bag into a large envelope or mailing bag (not padded), attach the appropriate postage, and send them to GAIN, Glennys Sanders House, Pride Parkway, Sleaford, NG34 8GL.

When we have lots and lots, we arrange to have them picked up to be recycled into plastic pellets and made into items such as benches and watering cans. As well as helping the environment, GAIN receives payment for all crisp packets recycled – so it's a win-win!

Why not get your
friends at work or
at school to join in?

Email your name & address to;

office@gaincharity.org.uk

and we'll send you a FREE
'Eat Crisps for Charity!' pack.

Sign up with TerraCycle UK as a
local collection point (naming
GAIN as the benefitting
charity) and once you have
collected at least 2 kilos, you can
have your crisp packets collected
by courier, free of charge

Full Circle: Volunteering for GAIN



GAIN peer support volunteer, Jon Shelton (right) with Adrian

I had Guillain-Barre Syndrome, the AMAN version, in 2009 and was in 3 hospitals for 4 and a half months in total, followed by 1 and a half years of physiotherapy and off work for 20 months in all.

I became a volunteer for GAIN prior to going back to work and have been talking to patients and families as and when required ever since. GBS is not a very pleasant experience for both patients and their families and I have found talking to them something positive that I have been able to do following a disease that has left me with some residual damage which thankfully doesn't stop me really doing anything, but I am not what I was. Nevertheless, compared to the starting point of complete paralysis from the neck down, I am certainly not complaining about where I am today.

Over the years the charity has changed to adapt to new communication technologies and particularly social media, to the point that the telephone helpline receives fewer calls as people are accessing the info they need via their computers and smartphones, and I am pleased to say there is a lot more info out there on GBS than there was even just 10 years ago.

Weird and debilitating disease

However, GBS is such a weird and often very debilitating disease that there is often a need for patients and/or families to talk to someone who has experienced the disease first hand.

After all these years of talking to people the common denominator is that it is simply impossible to comprehend the reality of GBS unless you actually experience it. That, and the fact that every patient's recovery and progress is different.

Positive impact

People really appreciate being able to talk to someone who has been through the shock and turmoil that they are collectively experiencing and to see someone who has recovered from a similar position to them, and you can see the encouragement it can give them. It has been very uplifting to have spoken to several patients who at the time were in disbelief about what had hit them and to see the positive impact that this can have. Most of the time this is by phone or email, but I have made a number of hospital visits over the years, however, the challenge here is often logistical as GAIN covers the whole of the UK.

I live very near to the Robert Jones and Agnes Hunt Spinal Injuries Hospital in Gobowen where I spent my last 3 months in hospital undergoing rehab after spending 8 weeks having excellent treatment (and every treatment I could and should have had) at the Walton Centre in Liverpool. Sadly, this is not always the case. I went to the RJAH for my rehab as my family were finding it difficult visiting me in Liverpool and the RJAH is on our doorstep. Over the years a few patients have appeared briefly at the RJAH before either being discharged or moved on as by definition it is not a

neurological centre and ordinarily GBS patients end up elsewhere.

I have got to know a lot of people at the RJAH in a variety of departments and in October 2018 I got an email from a Physiotherapist friend advising me that they had been treating a patient in Gladstone Ward (where I was treated) who had GBS and he would like to have a chat. So, having advised GAIN, in I went. Gladstone is a big ward so you can imagine my surprise when I was directed to the exact same bed that I was in! I introduced myself to Adrian and it was like stepping back in time, he was pretty much in exactly the same situation as I was in 2009 but unlike me had not been diagnosed correctly in the first place and various complications had impacted his recovery. My wife, Mel, works part time at the hospital and when I saw her that evening, I told her that I reckon I had “seen a ghost” and having visited Adrian on a few occasions she agreed that GBS had affected us both in an uncannily similar manner.

That was 3 months ago, and I have visited Adrian most weekends since. His progress has been excellent in my view (I am not a Doctor but can see there has been a lot of neurological activity, and as the nerves heal from the inside out the extremities are the last to fire up again). Like me, Adrian’s hands are not yet functional again and this is an immense source of frustration to him, as it was for me.

Psychological challenge

Adrian’s family are not that close by so a bit like me at Liverpool it is proving difficult for them to visit as often as they would like whilst managing all the challenges of family life and schooling etc., so I have got to know Adrian pretty well over the months and he should be very proud of the way he has approached the situation he finds himself in (I have to say that as he is much bigger than I am ☺). I am firmly of the view that the GBS journey is as big a psychological challenge as a physical one and having a positive mindset and environment is key to optimal recovery.

Adrian is now getting plenty of physio, OT and other therapies during the week hence I pop in at the weekends as this is when the hospital is much quieter. Christmas and New Year is a particularly difficult period as with all the bank holidays and weekends in between patients can sometimes have a lot of time on their hands at

a time which would normally be spent with their families. Adrian’s family was able to spend Christmas day with him which gave him a boost. I am hoping that Adrian will continue to improve sufficiently to relate his story himself to GAIN as I don’t feel he is that far away from using a computer and he is currently investigating the use of voice activated software.

During my visit to the hospital I became aware that the Occupational Therapy Department has used previously authorised pictures they had taken of me in their Departmental brochure showing me in my electric, head controlled wheelchair using a computer by both voice and foot controls as my hand and arms were the slowest to recover, so this was great to be able to show Adrian both where I was with my recovery at the time and also some of the options and adaptations that are available.

I have found all my volunteering work for GAIN very rewarding, and this particular journey especially so. Regularly being able to visit someone in a local hospital has been a real advantage and I would encourage anyone who is thinking of volunteering to do so.

Requests for peer support can be infrequent, and volunteers may go many months without a referral. There are, however, lots of supplementary ways you can support the charity and people affected by these conditions, including taking leaflets and posters to your local hospital or GP surgery, or by raising funds to help us deliver our services.

If you think you have what it takes to be a volunteer for GAIN, we’d love to hear from you.

Phone us on **01529 469910**
 Email: **office@gaincharity.org.uk**
 or apply online:
<https://gaincharity.org.uk/get-involved/volunteer/>



Caroline Wilson was struck down with Guillain-Barré syndrome less than a year after starting a family. She shares her story of the weeks following diagnosis

A plan postponed

In November 2011 I gave birth to a beautiful baby boy. It was a C-section delivery but as a fit 31 year-old woman I recovered quickly and had a very active and fun maternity leave. I was also training for the Great North Run the following September.

On 1st September 2012 I went for my final long training run before the race. I noticed some slight tingling in my feet afterwards but thought nothing of it. The next day I felt like I was coming down with a cold and had a really sore back and neck. One day later I was having trouble walking straight and could no longer climb the stairs.

I went to my doctor who referred me to a neurologist. I was extremely lucky to see the experienced neurologist that I did. He had seen several cases of GBS before and could diagnose me immediately. The most important thing he said to me was this "This could get worse, it could get much worse so that you can't even breathe anymore, but always remember it will get better again".

The next day I couldn't get out of bed anymore so my husband had no choice but to take me to the hospital. At the hospital they were very nice but completely clueless about how to treat a patient with GBS. One mistake they made was that they didn't realise the

weakness and paralysis was progressive, so they would wheel me up to the lunch table and not understand that I could no longer lift my fork. Or they would help me up to go to the bathroom and not realise that I could no longer stand on my own and I would fall to the floor. Even the senior neurologist dropped me on the floor when he was helping me back into the wheelchair after my EMG exam.

But the biggest mistake they made was that they didn't monitor my breathing correctly. And I didn't let them know that it was getting harder and harder to cough and keep my throat clear. After two weeks in the hospital, they decided to transfer me to a rehab facility to start my recovery.

Respiratory crisis

Unfortunately, as soon as I got there, I had a respiratory crisis and had to be sent straight back to the hospital, this time to the ICU. My breathing got so bad that they had to intubate me and then perform a tracheostomy. When I came round after two days I could no longer move my legs at all and was basically paralysed from the mouth down.

I remained this way for two weeks, only being able to communicate with the nurses and my family by blinking as they spelled out words on a board. I wasn't able to communicate the intense pain I felt the entire time. I was given IV morphine every hour and I spent most of the second half of each hour counting down

the minutes until my next dose. I also had no way of calling for help, as I couldn't push the call button. One night my arm fell off the bed and I lay there for an hour screaming in silence until the nurse who came to check on me noticed.

During this time those words from the neurologist came back to me over and over again and always gave me strength.

I was treated with two courses of IVIg and gradually as the days passed I started to regain some movement. First I could move my hands and lift my arms and then start to smile and move my mouth. I was taken off the respirator and able to breathe on my own again and talk again.

Then I was able to sit up with support for short periods of time. With every new movement came more intense pain. As the nerves started to regenerate I felt like my whole body was on fire, and my muscles had seized up from disuse.

Regular routine kept me going

My husband visited me twice a day every day that I was in the hospital and my parents came every day with my son. It was this regular routine that kept me going and stopped me from going mad.

Finally I was transferred to a rehab facility where I received regular physiotherapy as well as acupuncture treatment. I continued to improve and after five weeks I was able to get around in the wheelchair on my own and transfer in and out of bed.

During this time my son celebrated his first birthday. We had a small party in my room at the rehab centre with a few friends. It was the first time people had seen me since my illness and I could see the shock on their faces at the state I was in.

I was then transferred to a second rehab facility where I stayed for another four weeks. I made steady progress and by Christmas I was allowed home for a few days. Being home really brought back to me what I was missing out on and shortly after the New Year began, I asked to continue my treatment as an outpatient so I could be with my family.

Physically I made an almost full recovery in a little over a year. Although I still had problems with fatigue for a while after that. Now coming up to six years post GBS I can run and jump and two years ago I had a second child with a complication free pregnancy. I still have numb patches on my feet and they are very sensitive to cold and rough surfaces. My EMG results are still too poor to measure, but I am finally ready to tackle the challenge of the Great North Run in September 2018.

“This could get worse, it could get much worse so that you can't even breathe anymore, but always remember it will get better again”

Postscript

I feel very blessed. Not to have had GBS, but to have the knowledge and awareness that comes from having been in that position. And for the wonderful staff that looked after me. But most of all for my wonderful friends and family who supported me every step of the way.

I would like to raise money for GAIN in order to help raise awareness of GBS and improve diagnosis and treatment. Also to provide support for families whose loved ones are affected.



Caroline was as good as her word, raising £2185.13 plus Gift Aid for GAIN by completing the Great North Run in September 2018

A grand day for a grand opening

As you may have read in a previous edition of *gain4all*, GAIN has recently been able to purchase brand-new purpose-built premises.

Our new headquarters has been named in honour of the charity's founder, **Glennys Sanders MBE**, with the move taking us back to the town of Sleaford; home to Glennys and her husband, Howard, and where it all began back in the 1980s.

The weather was kind to us for the official opening on **Saturday, 26th January 2019**, and around 90 people came along to help us celebrate. In addition to the GAIN staff and Board of Trustees, we were pleased to welcome our Patron, **Sir Ian Macfadyen, KCVO CB OBE**, **Dr Jane Pritchard**, Chair of the GAIN Medical Advisory Board, retired Trustee **James Babington Smith**, **Councillor Richard Wright** Leader of North Kesteven District Council and **Mark Robinson**, Managing Director of Willow Homes, who built the premises and helped us move in. Friends and family of Glennys were joined by several of our members who either live locally, or who wanted to be part of history by making the trip to Lincolnshire!

Chris Fuller, Chair of the GAIN Board of Trustees said a few words before Glennys unveiled the plaque, officially opening the building. She was then presented with a bouquet and a sterling silver frame to hold a photographic keepsake of the day. A very large cake made by our Chief Executive, **Caroline Morrice** and decorated with the charity logo and a line of 'Moxies' (our charity mascot) was greeted with much enthusiasm and washed down with something cold and fizzy.

Everyone had a chance to look around the new premises and take a trip down memory lane as they studied our gallery of charity newsletters from 1987 to the present day, that is now installed in the corridor.

The main office incorporates a folding acoustic wall, allowing us to use it as one very spacious open plan room, or divide the space into a large office and boardroom. This flexibility, coupled with plenty of onsite parking, allows the charity to host conferences and other events, and even rent out part of this well-equipped and accessible building to other local organisations as an occasional meeting room. For further information, please contact us on 01529 469910.



From the top. 1. Chris Fuller, Chair of Trustees
2. Glennys Sanders, Sir Ian Mcfadyen, Councillor Richard Wright, CEO Caroline Morrice, Mark Robinson
3. Friends gather together to celebrate the opening of Glennys Sanders House



Top three photographs this page and previous page courtesy of Steaford Standard. All other photographs courtesy of Rebecca Ellis

Cochrane Review of effectiveness of exercise to prevent falls

Falls are a leading cause of accidental or unintentional injury deaths worldwide. Older adults suffer the greatest number of fatal falls and over 37 million falls are severe enough to require medical attention each year.

Exercise is frequently cited as a good way of helping to prevent falls, and now we have strong evidence that a programme of exercise can indeed prevent falls amongst older people living in the community.

New evidence has been published in the Cochrane Library, following a review produced by a team of researchers from the University of Sydney, Australia and Britain's Oxford University.

Systematic review of over 100 trials in 25 countries

The review summarises the results from 108 randomised controlled trials with 23,407 participants from across 25 countries. The average age of the participants in the studies was 76 years old and three quarters of them were women.

Eighty-one of the trials compared exercise of all types versus a control intervention (doing no exercise or minimal gentle exercise that is not thought to reduce falls) in people living independently at home, in retirement villages, or in sheltered accommodation.

Falls measured in two different ways

The review looked at two different ways of measuring falls. Firstly, they found that exercise reduces the number of falls over time by around a quarter (23% reduction). This means that if there were 850 falls among 1000 older people doing no fall-preventive exercise during one year, there would be 195 fewer falls among people who were undertaking fall-prevention exercise.

They also found that exercise reduces the number of people experiencing one or more falls (number of fallers) by around a sixth (15% reduction). For example, if 480 out of 1000 people experienced one or more falls over one year, participating in exercise programmes would reduce the number of fallers by 72 people.

Most effective exercise to prevent falls?

The review found that exercise programmes carried out in group classes or done at home prescribed by a health professional, such as a physiotherapist, or a trained exercise leader were effective.

Exercises were mostly done while standing, as this is the best way to improve balance and the ability to manage daily activities such as getting up from a low chair or climbing stairs.

Some effective exercise programmes also used weights to make the exercises harder.

The results of the studies varied, so the researchers assessed different types of exercise programmes to see how they compared.

Programmes that focus on balance and functional exercises provided strong evidence of fall reduction, while there was less certainty about programmes that include multiple exercise categories, for example balance and functional exercises combined with resistance exercises.

Tai Chi may also prevent falls, but there is uncertain evidence on the effectiveness of resistance exercises, including dance or walking, if not combined with balance and functional exercises.

Author, Professor Cathie Sherrington
from The University of Sydney,
Institute for Musculoskeletal Health:

“This evidence helps build an even stronger picture that exercise can help prevent older people having falls. It also illustrates which types of exercise can be beneficial. It is well known that keeping active promotes good health but this review pinpoints which types of exercise are more likely to be effective for preventing falls.”

Cochrane is a global independent network of researchers, professionals, patients, carers and people interested in health. It produces systematic reviews which study all of the best available evidence generated through research and make it easier to inform decisions about health. Their work is recognised as representing an international gold standard for high quality, trusted information. Visit <https://www.cochrane.org/>

For further reading and resources on fall prevention, exercises to improve balance and on predicting the likelihood of falls, visit www.independentliving.co.uk

Get fit for free

Can't afford gym membership? Don't want to splash out on fancy exercise equipment that will end up gathering dust? Pounding the pavement out of the question? There are lots of ways to build exercise into your life without splashing the cash, and definitely without the legwarmers or Lycra. Using MET values, you can even work out how many calories you're burning while you mow the lawn or do the shopping.

Did you know that NHS guidelines recommend adults* do 30 minutes of moderate aerobic activity at least five times per week, plus strength exercises that work all the major muscles on two or more days per week?

Clearly, in an ideal world, we'd all be breaking a daily sweat and having a good old cardiovascular workout to keep our hearts fit and healthy. The reality is that most of us fall short of the ideal, for a whole host of reasons.

However, every time we move, we are using muscle groups and burning calories, so even if your movement is limited, it still counts and it's still worth doing. Physical activity at any level can not only help keep your body healthy, it can also help you sleep, lift your mood, and reduce stress.

In 1993, *The Compendium of Physical Activities* was published to approximately code and score physical activity by use of MET values (Metabolic Equivalent Task). A MET is the ratio of the rate of energy expended during an activity to the rate of energy expended at rest. For example, MET 1 is the rate of energy expenditure while at rest, so a MET 4 activity expends 4 times the energy used by the body at rest.

To work out how many calories you could be burning off just by doing what you do every day, take your weight in kilograms, multiplied by the MET value of the activity, and multiply that by the number of hours spent doing the activity (multiply by 1 for 1 hour, by 0.5 for 30 minutes, by 0.25 for 15 minutes, etc). There are a few examples listed on this page, but there are hundreds more listed in the compendium, which is available to search online.

For the full list, visit;
<https://sites.google.com/site/compendiumofphysicalactivities/>

*aged 19-64

Walking (moderate) MET 3.3

Walk the dog, go for a walk in your lunch break or get off two stops early when you head into town. For those able to, walking is a low impact aerobic exercise that requires no special equipment and burns calories effectively.

Eg. a person weighing 75kg, walking (3mph) for 30 mins;
 (Weight x MET x hours)
 $75\text{kg} \times 3.3 \times 0.5 = 124 \text{ calories burned}$

Fishing, ballroom dancing (slow), playing guitar, bowling, sailing, washing the car MET 3



Bicycling (<10 mph), aqua aerobics, looking after a disabled or elderly adult (active periods only), pushing a wheelchair MET 4



Grocery shopping, washing dishes, ironing MET 2.3



Mowing the lawn MET 5.5



Moving furniture, carrying boxes, jogging MET 6

Vacuuming, unpacking or packing boxes, mopping MET 3.5

Dusting, food prep, putting away groceries, watering plants, playing with the kids (sitting), playing piano MET 2.5

Weeding, planting, cultivating the garden, brisk walking, painting walls / fence, carpentry MET 4.5

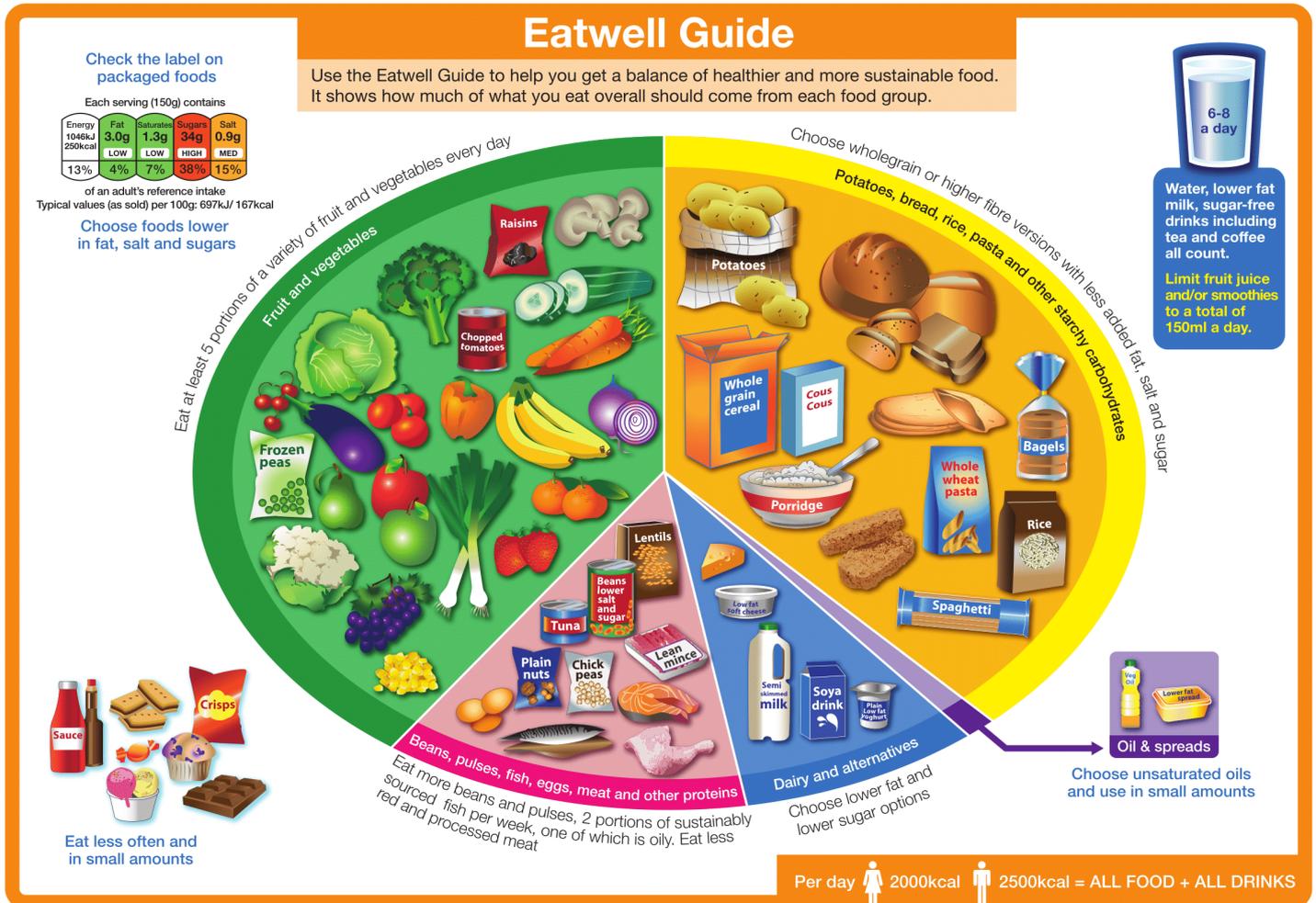


Childcare or playing with the kids or the dog whilst sitting, hairstyling, hatha yoga, motorcycling, billiards MET 2.5

Find exercise classes in your area for older people or for people with disabilities:

www.ageuk.org.uk/information-advice/health-wellbeing/fitness/which-exercise-might-suit-you/

Eat your way to a healthier you



Source: Public Health England in association with the Welsh government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

© Crown copyright 2016

We are often asked about diet during recovery from Guillain-Barré syndrome or living with a chronic condition such as CIDP.

There is increasing evidence that the microbiomes in your gut have a large part to play in matters concerning health and mood, with some being cited for combatting everything from obesity to depression. We're keeping an eye on research in this area and will of course keep you informed of any evidence-based breakthroughs that may benefit people suffering from inflammatory neuropathies.

In the meantime (even if you tend to be sceptical about the latest food trends and view every New Miracle Diet as nothing but a fad), opting for a balanced diet coupled with regular exercise, within whatever limitations you currently have, is a good choice for most people.

Keep a dairy. Make a note of foods that you either increase or cut down on, and whether there is any notable change in your energy and pain levels, physical capacity and mood. Bear in mind that any benefits from a change in diet may be very gradual. Include levels of exercise in your diary as this will also have an impact on how you are feeling.

Unless you have specific dietary requirements or preferences, the general advice for people affected by peripheral neuropathy is to follow recommendations in the NHS Eatwell Guide;

- 🍓 **Eat a wide range of fresh fruit and vegetables and choose whole grain / whole wheat alternatives instead of highly processed cereals, bread & pasta**
- 🍓 **Eat lots of differently coloured food as each colour carries its own compounds called phytochemicals, which are now believed to be beneficial to health**
- 🍓 **Reduce your intake of red meat by eating more lean poultry and fish (including at least one portion of oily fish per week) and replacing or supplementing meat with lentils, pulses and beans**
- 🍓 **Strictly limit fats, sugar, alcohol and processed meats**
- 🍓 **Drink at least 6-8 glasses of water a day**

For more on the NHS Eatwell Guide visit; <https://www.nhs.uk/live-well/eat-well/the-eatwell-guide/>

RED

Contain antioxidants including lycopene, anthocyanins, ellagic acid and astaxanthin.

Lycopene gives red fruits their colour. It is thought to have antioxidant properties that may help reduce blood pressure and cholesterol.

Cherries, cranberries, radishes, red apples, red grapes, red peppers, tomatoes, watermelon

ORANGE

High in carotenoids, such as alpha-carotene and beta-carotene.

Beta-carotene gives yellow and orange fruits and vegetables their colour and is converted to vitamin A in the body, where it helps us make hormones and keeps our eyes healthy.

Carrots, cantaloupe melon, mangoes, nectarines, orange peppers, pumpkin, sweet potatoes

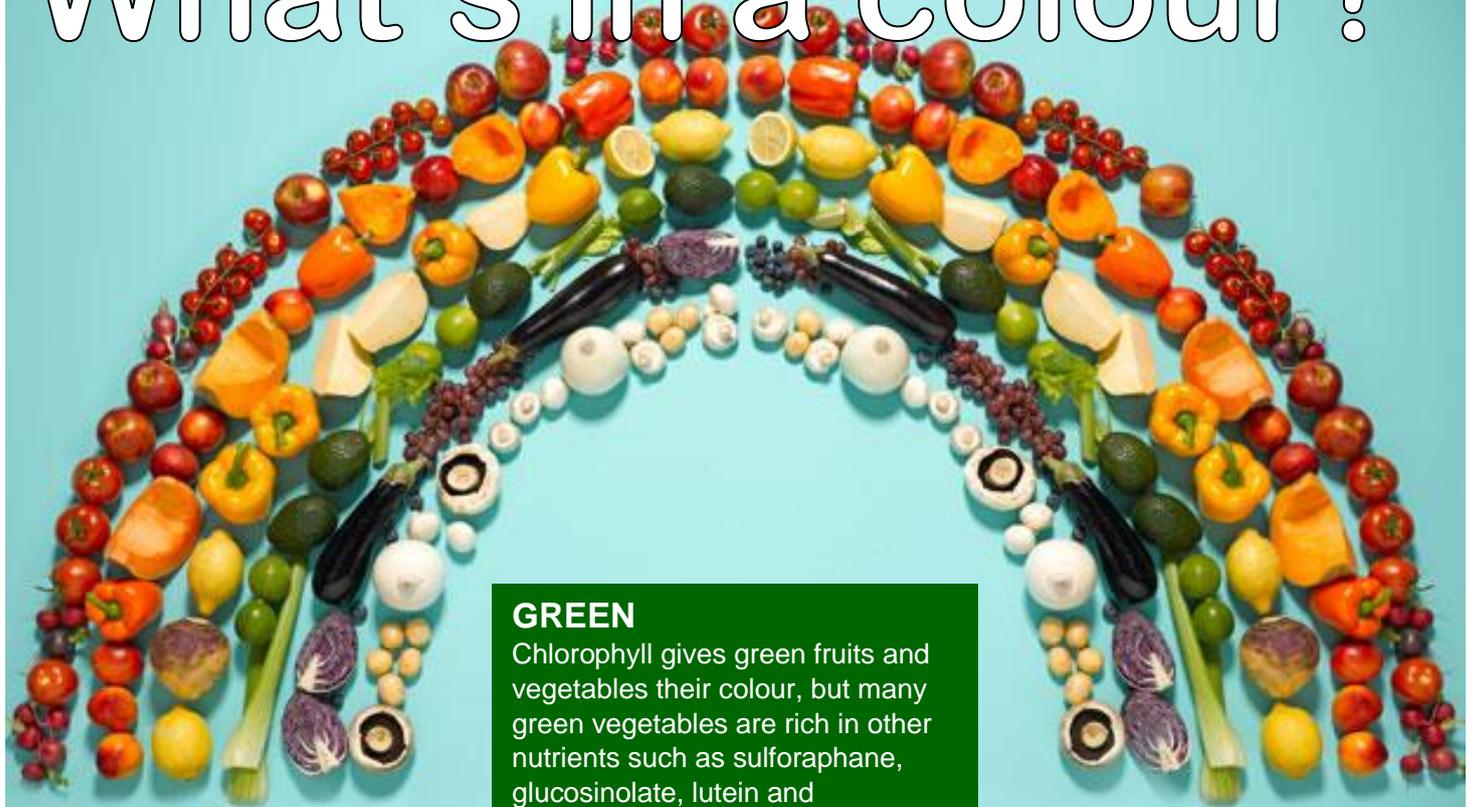
YELLOW

Contain carotenoids including beta-carotene and beta-cryptoxanthin.

As with orange fruit and vegetables, beta-carotene gives yellow varieties their colour. Like beta-carotene, our bodies can convert beta-cryptoxanthin into vitamin A.

Butternut squash, honeydew melon, lemons, papaya, peaches, persimmons, swede, yellow peppers

What's in a colour?

**BLUE / PURPLE**

Anthocyanins, giving blue and purple foods their rich colours are powerful antioxidants, which may have a role in protecting cells from damage. Nitrates are also present in many blue and purple foods as well as others.

Aubergines, blackberries, blackcurrants, blueberries, purple grapes, red cabbage, purple beetroot, purple lettuce

GREEN

Chlorophyll gives green fruits and vegetables their colour, but many green vegetables are rich in other nutrients such as sulforaphane, glucosinolate, lutein and zeaxanthin.

May slow the progression of age-related macular degeneration and help protect against blood-vessel damage and certain cancers, Researching whether sulforaphane could help protect against the damage caused by heart attacks, stroke and gestational diabetes.

Leafy green vegetables, apples, asparagus, avocados, celery, courgettes, cucumbers, green grapes, leeks, lettuce, limes, mange tout, sugar snap peas

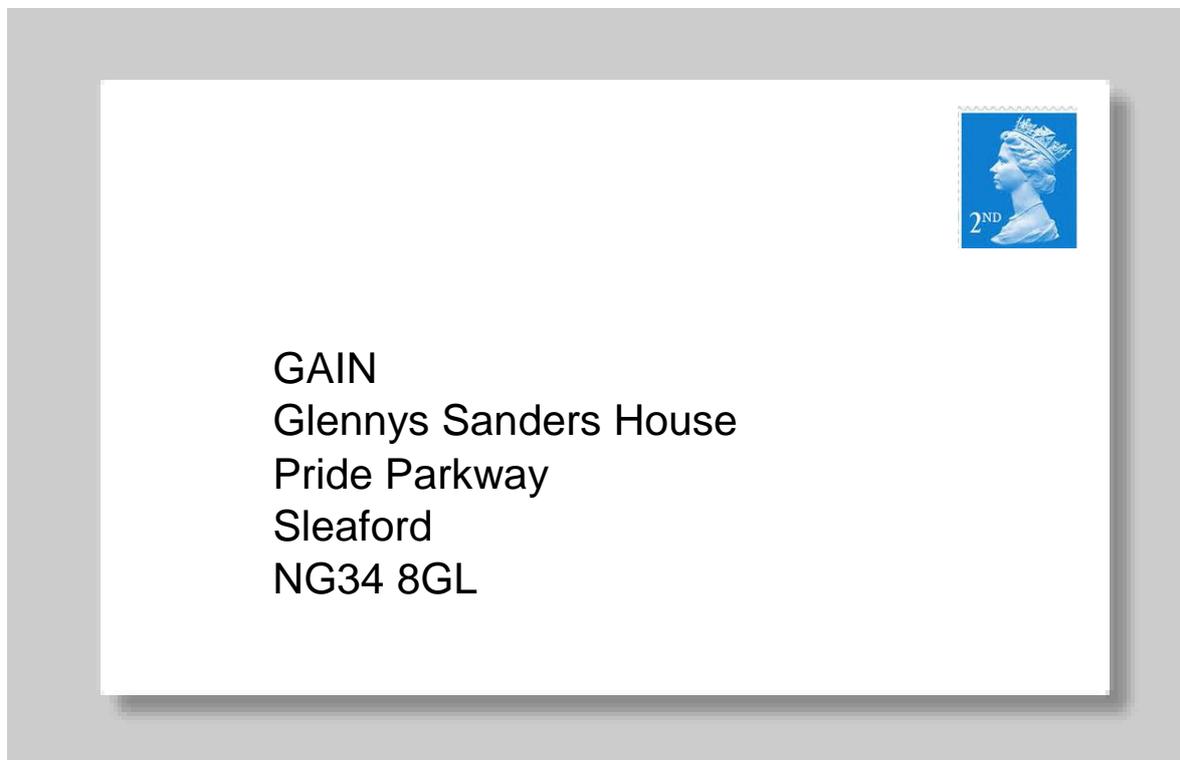
WHITE / BEIGE

Anthoxanthins are the pigments that create white or cream colours. Some studies have suggested that anthoxanthins may reduce the risk of Cardiovascular Disease and inflammatory conditions such as arthritis, but there is not enough evidence for these to be recommended over other colours.

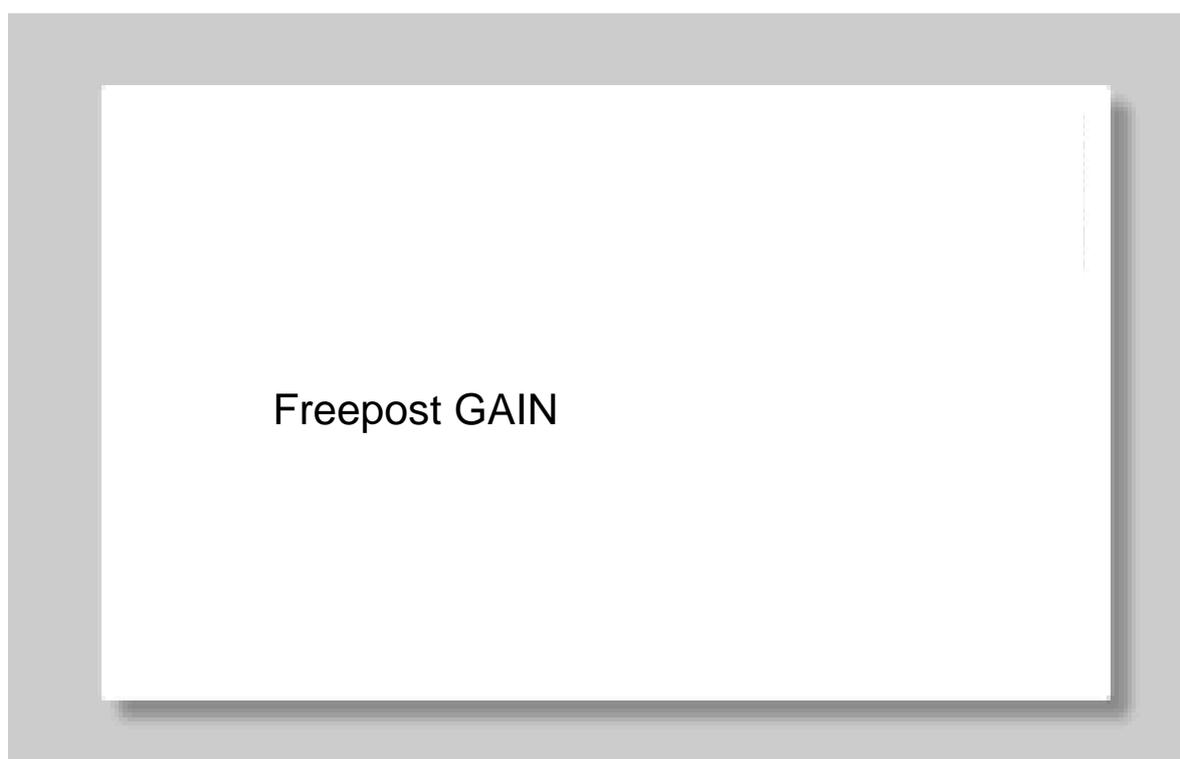
Bananas, celeriac, garlic, Jerusalem artichokes, mushrooms, onions, turnips, white peaches

Moving to our lovely new Head Office means we also have a lovely new address.

Please use our new address for all correspondence, not forgetting to attach the correct postage;



We also have a brand-new Freepost address, so if you are returning a membership form, voting slip or personal grant application, you may, if you prefer, omit the stamp and address the envelope as shown below;



HALL OF FAME

FUNDRAISING

Where would we be without our wonderful supporters who go that extra mile to raise funds and awareness for GAIN? You know who you are, but for everyone else's benefit, here are just a few examples of what you've been up to.

Anyone for rounders?

Alys McLoughlin, with the help of two of her friends and her teacher, organised a Pupils vs Teachers rounders match and charity event in July 2018.

Alys's younger brother, Owen, had Guillain-Barré syndrome when he was only 2½, and Alys wanted to raise money and awareness for the charity and conditions. The event went very well (the pupils won!), and they raised an impressive **£130.74** for GAIN.

*The girls who did the fundraising are from left to right Martha Tole, Alvina McAllion, **Alys McLoughlin** (all 12 years old) and their teacher, Miss Carter.*



On Boxing Day 2010 at the age of 54, **Jayne Moore** contracted Guillain-Barré syndrome after a dose of the 'flu. The illness caused short-term paralysis and she spent the following six weeks in hospital; intensive care, high dependency, and finally the stroke unit at Ysbyty Cwm Rhondda where she learnt to walk again. Jayne had intense physiotherapy and returned to work six months later.

*'I am lucky to have made a full recovery, and I now want to help raise awareness of this illness and how quickly it can develop and, in some cases, leave sufferers completely paralysed. On 27 September 2018, I hurtled head-first down the world's fastest zip line - **Velocity 2 at Penrhyn Quarry** - to raise funds for GAIN, the UK's only GBS/CIPD charity and help this charity continue its work in raising awareness about Guillain-Barré syndrome.'*



Jayne Moore (left) raised £150 (plus Gift Aid) by hurtling head first down Velocity 2

MARATHON MARVELS

This year, we were lucky enough to have no fewer than four people running for GAIN in the Virgin Money London Marathon! A massive THANK YOU for doing a phenomenal job, raising well in excess of £12,000 including Gift Aid in total!



OLIVER BRAY

GAIN silver bond runner, running in memory of his mum

£4,677 (plus Gift Aid) and counting of a £4,000 target!

'In September 2013 I lost my Mother, Kate to an extremely rare and acute form of Guillain-Barré syndrome. It was a great shock to all of my family. Mum went from having a common illness to complete paralysis, then us saying goodbye in the space of a few days. She was treated at the John Radcliffe Neurology department. At the time none of us had heard of Guillain-Barré syndrome, so I see running the London Marathon for GAIN not only as a personal challenge, but to raise awareness for this rare condition in my mum's memory.'

JADE ELTON

Public ballot place, running for her best friend's mum

£5,193.74 (plus Gift Aid) of a £3,000 target!

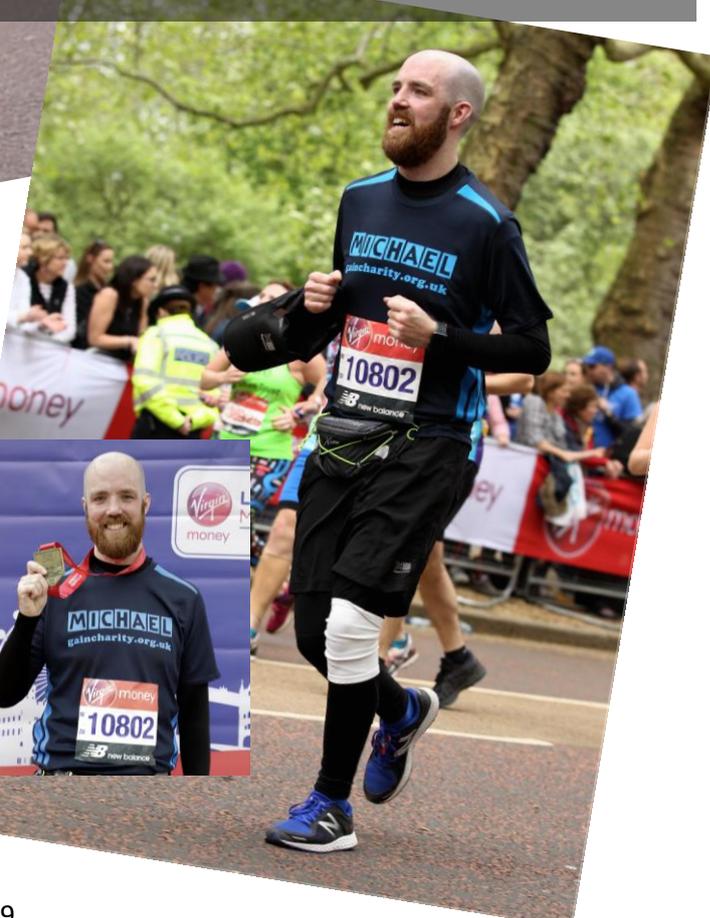
'Sadly, I have seen what this rare autoimmune condition can do to people. I will be running the London Marathon for my best friend's mum who has sadly been in hospital for just over 2 years. I will be wearing the shirt proud and trying to raise as much money and awareness to help people in the future.'



ASHLEY BOUTLOUP

Public ballot place, running GAIN to raise funds and awareness for GAIN because her cousin had GBS in 2016

£974 (plus Gift Aid) of a £500 target!



MICHAEL CHATTEN

Public ballot place, running for GAIN because his Dad had GBS

£820 (plus Gift Aid) of a £300 target!

'When I was one years old my Dad was diagnosed with Guillain-Barré syndrome. I was too young at the time to understand what was happening but since I have got older, I have heard the stories of how it affected my Dad and his recovery since.'

I would like to raise money for GAIN so that they are able to help and support families who find themselves in the same situation.'



Siobhan Hatch raised £83 (plus Gift Aid) by roller skating 26.2 miles!

Siobhan's 26.2 mile Skate Marathon

In 2014 I was diagnosed with GBS, I spent 2 painful weeks in hospital and further treatment outside hospital learning to walk again with a physiotherapist.

Unfortunately, I relapsed just a few months later which was almost fatal. This was when the doctors told me I had to give up my dance/gymnastics. I was beyond distraught. I'd always lead an active lifestyle and Dance was my life!

Determined not to be beaten by this disease I took my time to get better while still trying to remain positive. My friends helped me out at home with my children, as I still couldn't pick them up for cuddles or even bath them. Knowing my boys needed me was the spark I needed to fight.

It's now 2018 and not only am I dancing and back at gymnastics, but I now play Roller Derby for one of the North East's best teams Newcastle Roller Girls.

It's nothing short of a miracle that I'm here and I thank God every day for that.

Anthony Jennings Memorial Football Match

Four years ago we sadly lost our football coach Anthony Jennings, he suffered with CIDP and unfortunately the disease took him from his beloved family, friends and football club.

I arranged for a **Memorial Football Match** which took place on Sunday 7th October 2018 which involved all ex-football players which Anthony Jennings coached and managed through his extraordinary football career.

Anthony Jennings' family requested that all money raised on the day would go towards the GAIN charity as they feel that the charity holds a deep place in their hearts. On the day we held a raffle and an auction on some football memorabilia. We have counted up and we have raised **£600.00** for GAIN.

We will be making this an annual thing and look forward to raising more money for GAIN.

Jonathan Hartley October 2018



Anthony Jennings



Do the World for Charity

Virtue Money teamed up with the lovely staff of **Policy Services Ltd** in 2017 to do our biggest challenge to date...we ran, walked, climbed, cycled and swam around the World's Equator! That's right...over the past couple of years we have been traveling the distance of the World's Equator (24,874 miles) and for every mile completed by the members of staff, the company donated 50p to their chosen charities!

We are very proud to be reporting we have finally completed the challenge and in total, managed to raise £12,437 for the charities. Well done to all involved!

*Laura with GAIN's share of this phenomenal fundraising achievement – a whopping **£2,132.30!***

My Much Younger Sister



At 56 my sister was a very busy person. Working as a civil servant, giving 120% to her job and playing a key part in her first grandchild's care, enabling her son and daughter-in-law to be out at work and Karen could spend regular time with young Mary as she was growing up.

Around the middle of February 2017, Karen was feeling a bit under the weather. She had conjunctivitis and felt unwell. Whilst driving on Sunday 12th February she began to experience pain in her hands. Monday 13th February, Karen was looking after Mary for the day but still feeling unwell. She visited the chemist and made an appointment to see the doctor later that week. Karen's partner was able to finish work early enough to help with Mary towards the end of the afternoon.

During the early hours of Tuesday 14th February 2017, Karen was in a lot of pain and became worryingly unwell. As she says her body was telling her something serious was happening. She managed to phone her partner, get downstairs and unlock the front door for him. They were taken, by ambulance, to Royal Preston Hospital. Karen's condition rapidly worsened. Within a few hours she was in the Critical Care Unit, on full life support, where she stayed for over 190 days. Karen was diagnosed with 3 variants of Guillain-Barré syndrome and initially could only communicate with her eyeballs. Her eyelids had to be opened and closed for her.

Whilst in critical care, Karen did regain control of her eyelids and made good use of a selection of aids to enable communications using her eyes. Tiny steps of improvement have been happening since then but she remained in critical care because the strength needed to breath independently took a long time to return.

She became a patient of Rachel Moses (consultant physiotherapist) and Dr Vias and eventually the tracheotomy tube could be removed, and Karen spent about 4 weeks on the respiratory ward until her breathing was strong enough to go to the rehab unit in October 2017.

Karen was in Royal Preston's rehab unit for about 9 months before she moved to Cleveland House. She is an excellent patient and has handled her situation amazingly. She was very well cared for in Royal Preston and had wonderful therapists in the rehab unit.

Although understandably fearful, Karen soon settled in at Cleveland House and regards it as another step towards improving her mobility.

Living in the same area practically all your life can sound a little dull but has proven to be very fortunate in this situation. Close family, friends, colleagues, neighbours and hospital staff, who have become friends, are able to visit regularly.

When Karen first became ill we were advised that keeping the patients spirits up was important and that visitors would always be welcome. We had no idea then how long Karen was going to need 24-hour care. It has been a long time but, because of Karen, the care and support remain intact. She has been a pal to staff, patients and their families and through her we've met incredible people. Many people have supported her, but she has supported many people.

We have adjusted our lives to accommodate this unexpected situation in our family and the patient has kept cool and calm throughout it all and made our job easier than we would have thought possible.

Karen receives 24-hour care, including regular, good therapy sessions, at Cleveland House and is well looked after by all the staff. She has never had setbacks and continues to improve in small steps but is still confined to bed unless hoisted out by 2 people. Her body is very weak from the neck down.

During the past 24 months we have met a number of Guillain-Barré and CIDP patients and appreciate that the effects and recovery times are very variable, but we haven't met anyone who has been affected for so long and as severely as Karen.

If anyone reading this has any information or thoughts, they feel we may find helpful, please send me a message via the GAIN Head Office (email office@gaincharity.org.uk or phone 01529 469910) and it will be passed on.

Ann Pennington

A Father's Day that's hard to forget

This is my story so far.

It all started Saturday 16 June 2018. I awoke with a slight weakness in my left hand. I did not think too much about it as for about 10 days or so previous I'd had a stinker of a cold and assumed the weakness was related. The weakness had got gradually worse throughout the day. At about 6pm my wife and I took our dog to the beach for a run so all was well.

I woke at about 0730 on Sunday 17 June, Father's Day, I was to attend a charity motorcycle ride. I walked into the lounge and my legs gave way, I fell to the floor. I struggled to get up. My wife urged me to call NHS Direct. After about 15/20 minutes of answering questions I was directed to my local surgery out of hours number. They called an ambulance for me.

The ambulance arrived and with the assistance of the crew I managed to walk to their vehicle. They took me directly to A&E.

Various doctors asked questions and carried out tests throughout the day. At about 6pm two doctors asked to see me walk, with their assistance I managed a few steps, my feet and legs felt clumsy. I thought I was walking like a thunderbirds puppet. Little did I know this would be my last walk for some time.

That night I had two lumber puncture tests. I hate needles at the best of times.

Monday 18 June, I woke up and was barely able to move. By lunchtime I was paralysed and unable to move arms and legs at all. I was terrified. More tests and lots of baffled looks from the doctors

I think it was the Tuesday when I was told it was GBS. I had never heard of it before but at least I had a name for what was wrong with me.

Later that day or possibly Wednesday, time seemed a bit insignificant really, they started me on IVIG. This lasted for five days. None of my doctors or nurses had experienced GBS before so could not tell me much.

Sometime in the next few days I saw a specialist who was able to give me a more detailed explanation of what was wrong with me. Apparently, it was the cold I'd had that lead to GBS. I could barely take it in and even now cannot really believe what has happened.

I had never heard of it before but at least I had a name for what was wrong with me

The consultant told me I was to be transferred to a specialist neurological unit in Liverpool once a bed was available. About two weeks after first coming into hospital I was transferred to the Walton in Liverpool.

Unfortunately, my wife does not drive so was unable to get from our home in N Wales to Liverpool to visit me but hey I was in a specialist unit so my recovery would be quicker or so I thought.

Back to Bangor

I had no specialist treatment, all I received was a little physio care. I told my consultant that I thought it a waste of time being there. Surprisingly he agreed and I was transferred back to Bangor, at least I could see my wife daily.

I was told that as soon as a bed becomes available, I would be moved again, this time to a rehabilitation unit. On 20th July I was moved to Penrhos Stanly in Holyhead. It was a bit of a trek for my wife but at least here I was to get proper rehab care.

Movement was slowly returning to my arms and hands and was improving every week. Despite getting stronger and getting regular physio sessions, daily visits from my wife and visits from friends the nursing staff noticed my mood was dropping, hey I was still terrified and would cry myself to sleep most nights not knowing if I would ever walk again. After some discussion it was decided that with the right care plan in place I could return home. A provisional date of 02 October was set.

Thankfully the care plan was in place, I was to have carers 4 times a day as I was still unable to take care of personal hygiene or dress myself. I was however by now able to feed myself for the first time since Mid-June.

Home at last

On the second of October I returned home. The first obstacle encountered. I was in a wheelchair and the ambulance crew had to lift me and the chair up the 2 steps to out front door and then over the threshold. They then informed me they would not be able to get me in or out of the house again until a ramp was built. Luckily this was in hand and we were awaiting funding which was agreed and a week later a ramp was built.

The second obstacle was the care staff. We have thick carpets in the lounge which now houses my hospital bed and a hoist. The care staff claimed they struggled to move the hoist. It was agreed that rather than a portable hoist a gantry hoist would be installed.

The next obstacle was transport to hospital for my physio appointments. I was to have 12 sessions at a hospital in Caernarfon but due to unavailability of transport only received about half of these.

I have now been home for ten weeks and am now so much stronger. I still have carers for dressing and washing etc. I have an electric wheelchair which was funded by GAIN. I have just started a new course of physio for my upper limbs and I'm getting once a week physio for my legs at home.

Light at the end of the tunnel

I'm still terrified as no one knows for sure how much of a recovery I will make. There is however a bit of light at the end of the tunnel. Since June despite getting movement back in my arms and legs I have had no independent movement of my feet. Last week I was able to move my toes, not much but movement is movement. If I keep on like this I will soon be back at work.

My advice for anyone who suddenly finds themselves in this position is do not give up. It is a long and slow process, but you will recover.

Six months on from when this all started, I would like to take this opportunity to say thank you to my wife and family for all their support, to my brother and his mates for the charity night they held to raise funds for my exercise machine etc and to my friends for their visits. I would not have come through this without such good support. Thank you too to all the nurses and care staff that have looked after me since June.

Michael Plumb



GoRaise



GAIN has partnered up with GoRaise, so it's now easier than ever before for our supporters to join us in fundraising.

You can get free donations every time you shop online.

It's simple, it's safe, and it doesn't cost a penny.

Once you've registered with GoRaise, every time you shop online at thousands of brilliant online retailers - including M&S, John Lewis, Argos, Ebay, Sports Direct, & Expedia - those retailers will donate a portion of what you spend to our cause, for free. So, how do you get started?

Just go to our page at <https://www.goraise.co.uk/GAIN/?refid=7253> and register for free today.

Once you've done this, just make sure that you visit the GoRaise website and click your chosen retailer, from the list of over 3,000, each time you want to shop online.

If you like shopping online, please do sign up today. It will make a huge difference to us and we could raise £1000's of extra funding every year just from donations generated by ordinary, everyday online shopping.

Thinking of doing a fundraising challenge for GAIN?

People take on all sorts of challenges to raise money for charity, from skydiving to climbing Mount Kilimanjaro, and we find that it can be a very effective way of raising both funds and awareness for the charity, really capturing the imagination of friends and family.

Once you decide what to do and which company to do it through, you will have the option to pay for it yourself or ask the charity to pay for it on your behalf out of your fundraising. We are usually ok with this, but for ethical reasons, we ask you to raise at least as much for charity as the cost of the challenge, and also that you make it very clear to your sponsors that £XXX of donations will pay for you to actually do the challenge!



There lots of companies out there who organise challenge activities. If you want to cover the cost of your challenge from fundraising, please always let us know what you plan to do before you book your place, to make sure we are happy for you to go ahead.

Attention all fundraisers! Introducing GAIN's new online fundraising platform of choice....



Online platforms such as Just Giving, Virgin Money Giving and GoFundMe are now the most popular options for collecting sponsorship money and donations.

Fundraising pages are easy to set up and share via social media, and donations are paid to your chosen charity automatically, so you don't need to chase your sponsors to cough up after the event.

BUT they come at a price, with monthly fees paid by participating charities and percentage transaction fees paid from donations or Gift Aid claimed. At least, it always used to be that way.

The Wonderful Organisation does things a bit differently.

This fundraising platform is genuinely **fee-free**, to our fundraisers, their supporters, and to us, as the benefitting charity.

The service only exists because of the support of corporate sponsors (Wonderful Partners), who generously contribute financially and in other ways so that every donation made to a charity can be passed on to that charity in full.

If you are planning on doing a spot of fundraising for GAIN, please consider setting up a Wonderful fundraising page to collect your donations.

"In terms of maxing your cash, you can't beat Wonderful.org. It doesn't charge any service or processing fees to the charities, meaning 100% of your donation goes directly to doing good."
Money Saving Expert

Wonderful is a not-for-profit company limited by guarantee, incorporated in England and Wales, registered number is 09818383.

<https://www.wonderful.org>

South West England, October 2018

Sixteen people enjoyed a most informative and sociable meeting of the South West group in Yeovil on 27th October 2018.

William Harmer, a GAIN trustee, opened the meeting with an update from GAIN Head Office. He then told us of his personal journey from initial GBS symptoms to recovery, which many of us could relate to.

Our guest speaker of the day was Jane Robinson who co-founded the Nine Springs Natural Health Centre in Yeovil and who has been a qualified practitioner in Traditional Chinese Acupuncture for almost 40 years. Jane began by clarifying the spectrum of complementary therapies (also known as alternative or integrated therapies). These are used in conjunction with conventional medicine to manage health conditions and as our symptoms are seldom identical they offer a more flexible approach.

She grouped the categories of therapy available:

- Physical (massage, physiotherapy, osteopathy, reflexology, occupational therapy)
Medicinal (homeopathy, herbal medicines, supplements, nutrition)
- Talking (cognitive behaviour therapy, counselling, psychotherapy, psychiatry)
- Movement (exercise, yoga, Pilates, Tai Chi, Qi Gong, meditation)
- Combined Approach of Chinese medicine (acupuncture, Chinese herbs, osteopathy and massage, and meditation)

Jane explained that acupuncture is used as a way of dealing with “stuck” pathogens. It affects the mind as much as the body by stimulating the acupuncture “command points” which in turn stimulate endorphins which are the natural opiates of the brain. Treatment usually takes place initially on a weekly basis for 6 weeks (the time taken for a body to replace cells) and, following assessment, may be continued on a fortnightly or monthly basis. To find a suitable therapist it is important to not only check for appropriate qualifications and insurance (can be done through internet) and personal recommendation, but also to meet with the therapist to establish if you are comfortable with them and can trust them to help you on your journey to better health.

Jane also advocates eating “blood nourishing” foods and suggested that an anti-inflammatory diet may be useful for GBS/CIDP. She listed foods for nourishing and helping with nerve growth and referred us to a helpful book “Recipes for Self Healing” by Daverick Leggett.

Jane kindly stayed on to offer personal practical advice, and we all enjoyed tea and homemade cake followed by our usual raffle and the opportunity to buy GAIN merchandise and Christmas cards.

Meetings are held in the South West of England in March and October each year, & we try to offer a variety of locations in order that people from around the region may be able to attend at least once every 12-18 months. If you know of an accessible venue and would like to help organise an event near you, please contact GAIN head office with your details.



Do you live in the North West of England? Would like to meet up with other people who have been affected by Guillain-Barré syndrome, CIDP or one of the variants?

The Lancashire and Cumbria local branch of GAIN hold quarterly meetings in March, June, September and December each year, in Bilsborrow Village Hall, just north of Preston.

Coming up in 2019

Saturday, 15th June
AGM & Plant Sale

Saturday, 14th September
Speaker (to be announced)

Saturday, 7th December
Christmas Party & Jacob's Join

All meetings start at 2pm and you can be assured of a warm welcome.

Refreshments available.

If you would like to organise a gain2gether in your area, please contact us. We would love to hear from you!

Phone Simon or Gill on 01529 469910 or email us at office@gaincharity.org.uk



Dedicated to helping people affected
by Guillain-Barré syndrome, CIDP & the
Associated Inflammatory Neuropathies
www.gaincharity.org.uk

If you have been affected by **Guillain-Barré syndrome**, **CIDP** or one of the related conditions, come along and meet up with others who understand the issues faced by you and those close to you.

gain2gether North East England meets at
1.30pm on the 3rd Tuesday of every month*

Walkergate Park
Centre for Neuro Rehabilitation and Neuro Psychiatry,
Benfield Road, Newcastle upon Tyne, NE6 4QD

**except June and December*

Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) is a registered charity nos. 1154843 & SCO39900

Glennys Sanders House, Pride Parkway, Sleaford, Lincolnshire, NG34 8GL
Tel 01529 469910 or Email office@gaincharity.org.uk (Monday to Friday 9am-3pm)

We received this account of coping with a diagnosis of Guillain-Barré syndrome from a lady aged 71, who, despite making an incomplete recovery to date, remains positive and optimistic about the future.

I was walking down the High Street to do some shopping at the end of August 2017, when I felt a strange sensation down the left side of my body. I carried on and completed the shopping, but by the evening I could hardly walk on my left leg. The next day, the same thing happened with the right side of my body, and by that night, I could hardly get into bed.

I awoke the next morning to find I was totally paralysed from the shoulders down and could only move head and neck. It occurred to me that, in this situation, I could have panicked or felt fear and despair. But I've been a Christian for many years, and all I actually felt was perfect peace. I heard the Lord say, "I'm going to take care of you", and I've had peace all through my time in hospital, except for two of the weeks that I was in Intensive Care.

I had deteriorated to the point where I was on a ventilator, with a tracheotomy tube, because my breathing muscles were now also paralysed, so I couldn't breathe on my own. I had a chest infection, bowel infection, urine infection, and had lost my hearing and wasn't able to whisper more than two words at a time. I couldn't ring the bell if breathing became too difficult, and I was in a side room (that was the only bed available), where I couldn't be seen. The staff reassured me that they would keep looking in, but being so busy, it didn't seem to happen when I had the most difficulty in breathing. When I cried out in my thoughts to the Lord, someone always came, and after six weeks, I was able to go on to the main part of the ward.

My recovery from Guillain-Barré syndrome, as they finally diagnosed it, has been step by step, with wonderful care from the nursing, physiotherapy, and other staff. So now I am walking with callipers and a Zimmer frame, and doing nearly everything for myself. I am telling everyone what a peaceful journey it is, and very interesting too.

The hospital I have been transferred to has marvellous carers and excellent therapists, and I have discovered a desire to write children's stories and have written eleven to date. I have done the illustrations as well, and people keep saying I should publish them – so we'll see.

I have been in hospital now for eighteen months but am due to be discharged in a few weeks. Although the illness was classified as acute, and I was warned I might only have a 50% recovery, I will only accept having a complete recovery. I am almost there, apart from putting on my callipers and socks myself, and managing stairs. Otherwise I am very active and self-sufficient.

Brenda Ralph



Here at GAIN we do our best to provide the information and support you need, even if that means signposting you elsewhere

These are a few suggestions for other organisations who may be able to help

<p>www.carersuk.org Helpline 0808 808 7777 10am–4pm Mon & Tue</p> 	<p>www.carers.org carerstrust action · help · advice</p> <p>money & benefits, support for young carers, health & wellbeing, working & learning, out & about, getting a break, legal & rights</p>	<p>OPEN 7 DAYS PER WEEK </p> <p>Carers Direct Information, advice and support for carers</p> <p>You can call the Carers Direct helpline on 0300 123 1053 if you need help with your caring role and want to talk to someone</p>
 <p>www.familycarers.ie</p>	 <p>Benefits Work Money Consumer Family Housing Legal Immigration Health</p> <p>www.citizensadvice.org.uk</p>	<p>Citizens Information Phone Service Mon-Fri 9am-8pm 0761 07 4000</p>  <p>Citizens Information</p> <p>www.citizensinformation.ie</p>
<p>contact <i>For families with disabled children</i></p> <p>WE ARE CONTACT, THE CHARITY FOR FAMILIES WITH DISABLED CHILDREN</p> <p>We support families with the best possible guidance and information. We bring families together to support each other. And we help families to campaign, volunteer and fundraise to improve life for themselves and others.</p> <p>www.contact.org.uk</p>	<p>FacialPalsy^{UK} INFORM • SUPPORT • RESEARCH</p>  <p>Inform Support Research</p> <p>www.facialpalsy.org.uk</p>	 <p>Advice / Information / Jobs / Volunteering Projects / Programmes / Training</p> <p>www.disabilityrightsuk.org</p>
 <p><i>Somewhere to turn when someone dies</i></p> <p>Helpline 0808 808 1677 www.cruse.org.uk</p>	 <p>Links and information for people with pain</p> <p>www.britishpainsociety.org/people-with-pain/</p>	 <p>Information & support for people living with chronic pain</p> <p>Self-management / Events & meetings Support phone line / Online library</p> <p>www.chronicpain.ie</p>

If you know of any useful organisations not listed here, please let us know about them

MOXIE NEEDS YOU



EAT CRISPS FOR CHARITY

If you would like to get involved in our crisp packet recycling scheme to raise funds and awareness for GAIN (whilst doing your bit for the environment), please email office@gaincharity.org.uk with your name and address and we will send you a free kit

Further details inside

**PLEASE EAT CRISPS
RESPONSIBLY!**