



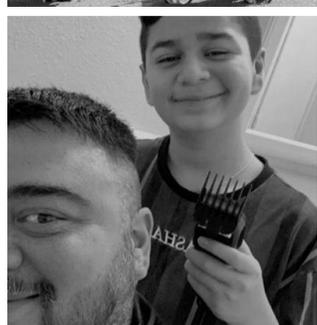
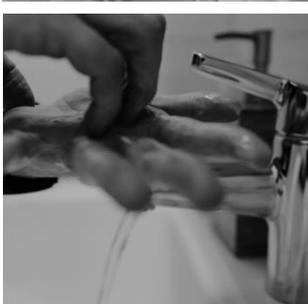
gain4all

For people affected by GBS, CIDP & the associated variants

2020

CANCELLED

The year nothing happened
...and everything changed



Safe Travels

Essential worker

Yes	No
↓	↓
Okay to ride	Why are you even here reading this?
	↓
	Go home.



Special edition looking at the impact and implications of the coronavirus / COVID-19 pandemic and what you're doing to help

Summer 2020

Dear Members and Friends

Welcome to a special edition of gain4all which addresses some of your questions regarding COVID-19, and takes a look at the impact of the pandemic on the UK's charities. This magazine replaces the monthly newsletter for July, so the next one will be produced towards the end of August.

We'd like to kick things off by saying how grateful we are to everyone responding to our appeal to plug the income gap left by the cancellation of fundraising events across the country. Hundreds of you got busy donating, fundraising, saving crisp packets, raising money when shopping online or by selling unwanted DVDs and books.

Thanks also to everyone who was able and willing to switch over from postal to email newsletters, and to everyone who attached a stamp when returning their membership form. Between you, you're saving us hundreds of pounds, which is now more crucial than ever.

Although we're not out of the woods yet, this vital support will help us to keep operating, reaching out to patients and their families across the UK and Ireland when they need us most.

Your generosity and kind messages mean the world to us.

Thank you,

the GAIN team



Do you have a story you would like to share with our readers? Please email submissions for the next issue before **1st September 2020**:

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

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Photograph by Martin Sanchez

Other cover photographs (left to right from top);

Nick Fewings, n/a, Lisa Bresler, n/a, Edward Howell, Jan Kalkuza, Nathan Reboucas, Mick Haupt, CDC, n/a, John Cameron, Daniel Lee, n/c, Matt Seymour, Dan Burton, n/a, Gary Butterfield, n/a, Jan Kalkuza, Daniel Lee, n/a (n/a = not accredited)

What does coronavirus mean to me?

We continue to receive enquiries from people wondering whether they're more at risk from coronavirus and COVID-19 because they've had Guillain-Barré syndrome.

Having had GBS or an acute variant, or living with CIDP or a chronic variant, does not in itself damage or weaken your immune system. There is no evidence that you are any more likely to catch coronavirus, or develop severe symptoms, including those of COVID-19, than anyone else.

However, there may be other factors to be considered, such as age, other underlying health conditions, certain ethnicities, or taking corticosteroids or other immunosuppressant medication, which might mean you are more vulnerable than other people.

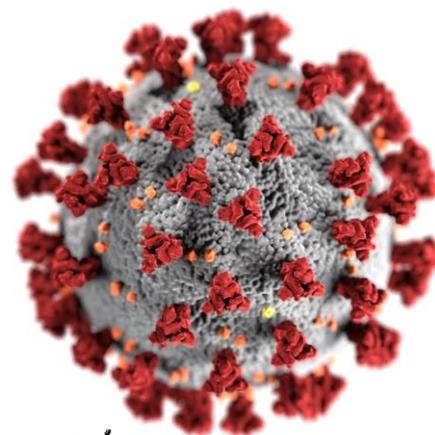
If you received a letter at the start of lockdown, advising you that you are considered to be extremely vulnerable, then you should continue taking the extra precautions recommended for people who are shielding.

If you aren't shielding, you need only take the same precautions as everyone else. This includes regular washing of hands, or using hand sanitizer if soap and water is unavailable, staying at home as much as possible, working from home if your job permits, avoiding public transport if you can, and wearing a mask in any situation where social distancing is not possible, including on public transport if you must use it. Here at GAIN, we would recommend wearing a mask in shops and other indoor spaces as well as on public transport, as it helps to keep other people safe as well as possibly giving you a small amount of protection.

This advice stands at time of writing and may be subject to change.

Two metres or not two metres?

Although the two metre rule has recently been revised in England in readiness for bars, restaurants and hairdressers to open up, this does not mean it's ok to get up close and personal with other people again. The new rule being rolled out is 'one metre plus', with the recommendation that a distance of two metres should still be maintained where possible.



What are the current restrictions?

Restrictions are gradually being eased, but the rules vary from nation to nation, and are too complex to list here.

In addition, there are likely to be localised lockdowns reinstated where a spike in new cases is identified.

To be sure of the most up to date advice, check trusted news sources or government websites for the latest guidance where you live.

Northern Ireland

<https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19>

Scotland

<https://www.gov.scot/coronavirus-covid-19/>

Republic of Ireland

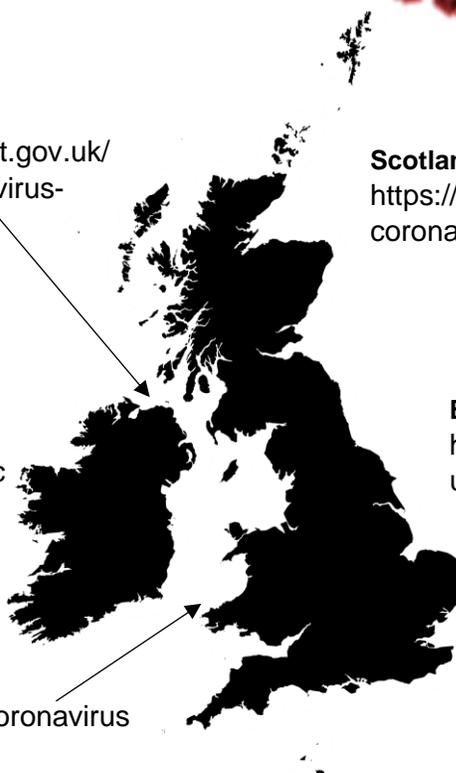
<https://www.gov.ie/en/campaigns/c36c85-covid-19-coronavirus/>

England

<https://www.gov.uk/coronavirus>

Wales

<https://gov.wales/coronavirus>



What does coronavirus mean to GAIN?

Our first thought when the coronavirus pandemic reached us here in the UK was how best to safeguard staff, volunteers, patients and members. Before lockdown was even announced, we took the decision to replace peer support visits with a phone call or video call and to postpone all branch and other face-to-face meetings indefinitely. We set up a rota to ensure only one member of staff at a time would be in the office, installed a hand-sanitizing unit at the entrance to the building, and imposed a 'no visitor' rule. The inevitable announcement came soon after. Schools closed, and the UK was in lockdown.

Since then, the GAIN team have been mostly working from home, only venturing into the office to send out support packs, to print off and post newsletters, and to pick up the post. Instead of taking our online world for granted, we began to truly appreciate the technology that allows us to carry on as normal from our kitchen or dining table. We all have secure access to the database, files and office email, and phone calls to the office are redirected to our mobile phones. We quickly adapted to new working practices, starting each day with a video conference to catch up with one another and make sure all bases are covered.

Once logistics were sorted out, it quickly became evident that the pandemic would have a devastating impact on the charity sector, as travel and social distancing restrictions were put in place and thousands of mass-participation sporting events and fundraising challenges were cancelled or postponed.



Zero income from the many marathons, half marathons, 10k road races, mountain treks, Tough Mudders, Kilt Walks, Ironman challenges and more meant we were looking at a potential shortfall of many thousands of pounds.

In the first couple of months of the fiscal year, the threat became a reality, with income down by approximately 60% compared to the same period last year. However, the generosity shown by our members and supporters in responding to our appeal for help, and when returning membership renewal forms, is helping us plug the gap.

We are confident that with your continued support, along with reducing costs where possible and taking advantage of the Government furloughing scheme, we will stay afloat and keep operating.

Thank you to everyone who is helping us weather this storm. We couldn't do what we do without you.

Charities face a £12.4 billion shortfall in income this year

New findings on the impact of coronavirus on the charity sector

According to the Institute of Fundraising and Charity Finance Group, charities are facing a huge predicted loss to their income as they continue to grapple with the impact of the coronavirus pandemic and continued social distancing measures.

The analysis comes following the publication on 19th June 2020 of the results of a recent survey of charities reporting financial loss and reforecasting of income for the year ahead. On average, respondents to that survey reported that they were expecting a reduction of 24% to their total income for the year, which would mean a £12.4bn loss of income if the average was applied to the sector as a whole.

During lockdown (23rd March – 12th May 2020)

- 84% of charities reported a decrease or a significant decrease in their total income
- 92% of charities reported a fall in trading income with just 5% reporting that income from trading had increased

When looking at the year ahead, charities:

- Expect to see their total income significantly reduced, with their total income on average 24% lower than previously forecasted
- Are planning on an average fall of 57% on trading income
- Have revised their voluntary income for the year down by an average 42%

Sunday 26th April 2020 should have seen thousands of runners pounding the streets for the 40th London Marathon. Instead, a challenge with a difference was launched.

The COVID-19 pandemic has had a catastrophic effect with the cancellation of thousands of events and the loss of billions in income through fundraising events. The Virgin Money London Marathon alone, which should have taken place on Sunday 26 April, is the world's biggest one-day fundraising event, raising more than £66.4 million for thousands of charities in 2019.

Virgin Money came up with the idea of setting yourself a challenge around the numbers 2.6 or 26 to raise much needed funds for your favourite charity and hopefully have some fun at the same time. Lots of you got on board, raising a fantastic amount of money in the process!

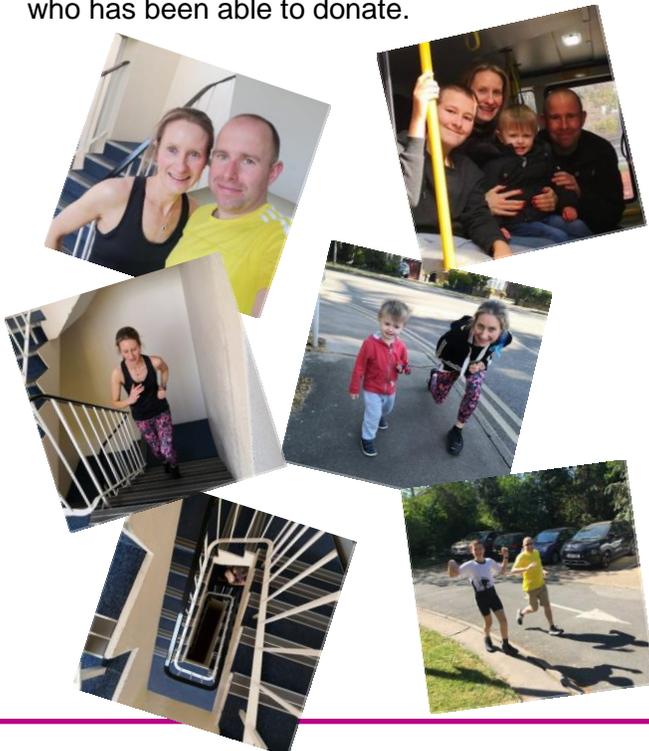


Naomi Hillman's 2.6 challenge was to walk along a wobble beam 26 times in succession, and to donate £26 to GAIN. Naomi has CIDP and her balance is poor, so this was no mean feat. She sent us a video of her completing her challenge, which we found truly inspirational. Well done, Naomi, and thank you for sharing your achievement!

2.6 CHALLENGE ACCEPTED

Thank you, Team Speed! You raised £393.75 including Gift Aid!

Team Speed has completed our 2.6 Challenge! Mark and Sarah ran 26 flights of stairs which was just over a mile each. Harley's 26 laps covered just under 5 miles running-walking. Jack's 2.6 laps came to a quarter of a mile of running. We have all enjoyed ourselves and are very grateful to everyone who has been able to donate.

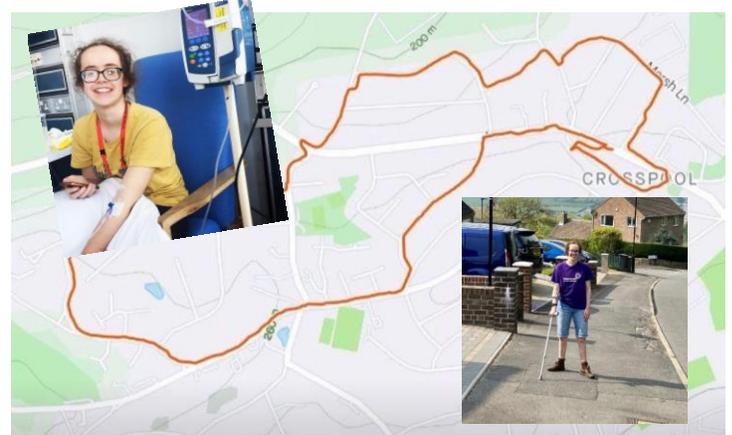


Olivia has raised £137.15 for GAIN

Olivia's Story - I have CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) and walking provides important physiotherapy to help with my mobility.

I've been walking at least a mile a day every day since lockdown started (I did 14.5 miles during the twelve days of lockdown in March and have been out for my daily exercise every day in April so far).

I have been helped throughout my illness by GAIN, and I am under the Neurology team at STH which is supported by Neurocare, so I decided that for my 2.6 Challenge I will walk 2.6 miles on Sunday 26th April, which is significantly further than my usual daily exercise - contributions will be split 50/50 between the two charities.



Where there's muck, there's money!

GAIN's very own Chief Exec, **Caroline Morrice**, persuaded friends to sponsor her to spend 2.6 hours cleaning her own house (not a favourite pastime), raising a phenomenal **£714.98** including Gift Aid!



Thank you, Liz Ramsay, for Nordic Walking 26 minutes each day, and raising £188.61 What a fantastic effort!

For her 2.6 challenge, Gabby Victor did a 26 volley rally, raising £265. Thank you, Gabby – you're amazing!

Maria and Lucie raised £307.25 by walking 2.6km every day for 26 days! Fabulous!

There isn't room here to mention everyone, so a big Thank You to anyone we've missed!

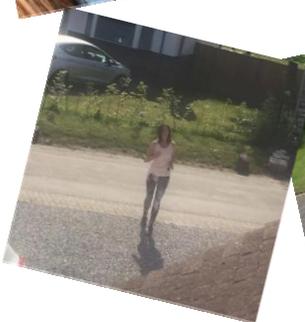
Lisa's 2.6 Challenge was to cycle 26 miles in as few days as possible, sticking to the government guidance of 30 minutes cycling per day.



Well done and thank you, Lisa, for raising £495!

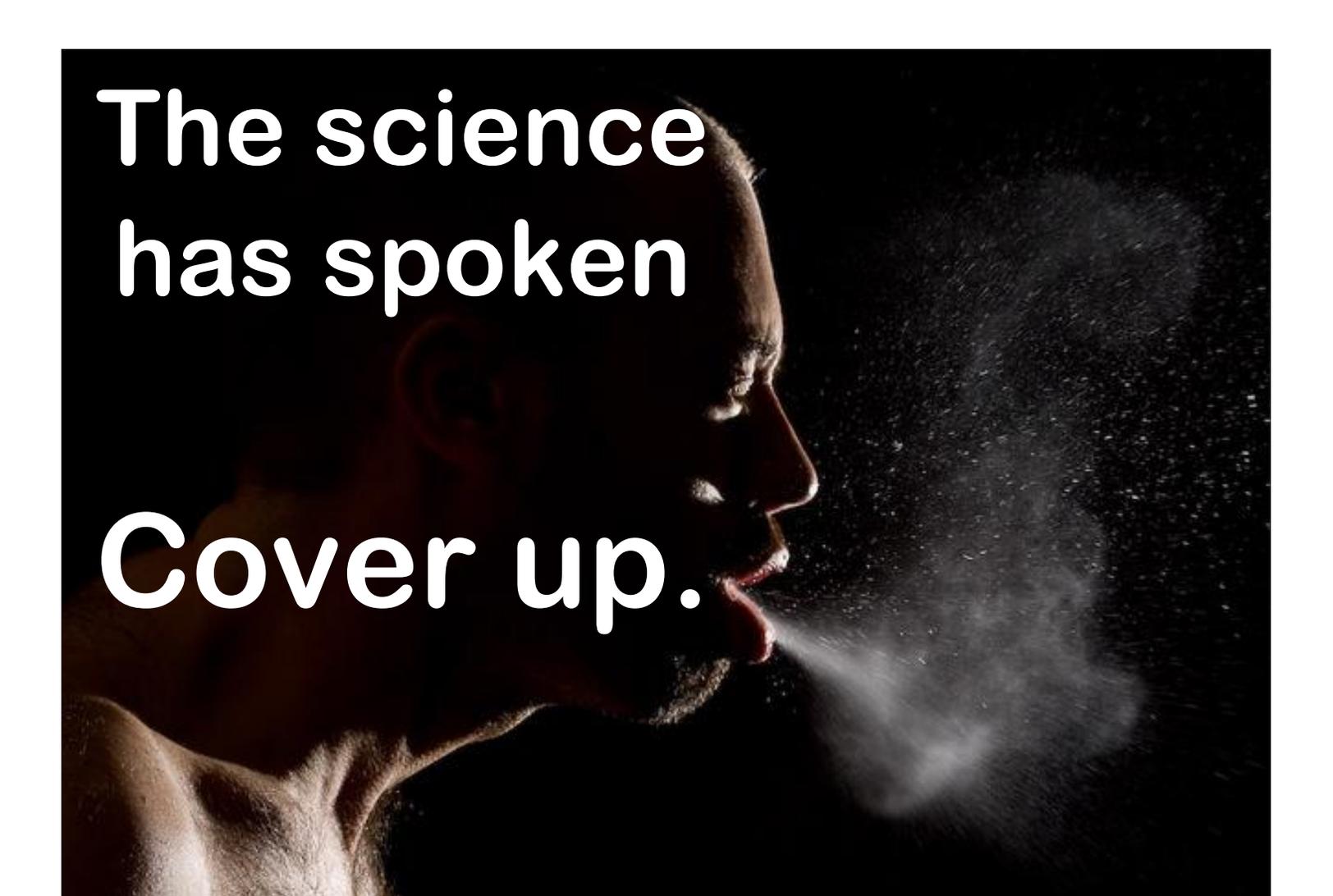


Sarah Clements of ACES Marketing (a company that works with and supports GAIN) decided to get her whole community involved, challenging neighbours in the village of Horsley in Surrey, to complete a virtual London Marathon! A massive thank you to everyone who took part, come rain or shine!



All your challenges raised **£7,250**

Thank You!



The science has spoken

Cover up.

Right from the start of the pandemic, many people around the world decided to wear a face-covering to help prevent the spread of COVID-19. This is quite normal in some countries, where new virus outbreaks are a relatively common occurrence, but here in the UK, there has been and continues to be some resistance to the idea.

Conflicting information abounded; on one hand, we were hearing how the lack of PPE was endangering NHS and care staff, whilst on the other, we were told there was no evidence that wearing a mask by members of the public prevented the spread of infection.

The lack of clear advice may have been down to a fear that the public would snap up resources required on the front line. This, coupled with an assumption that we would wear masks incorrectly or that we would be given a false sense of security, meant that for months, both the World Health Organisation and the government failed to issue a recommendation to cover up.

Recently, however, new evidence has come to light that coronavirus COVID-19 is indeed spread by tiny droplets in the air, not only when coughing or sneezing, but also

when talking, singing, shouting and breathing heavily. Wearing a face covering helps to reduce this spread.

As it now appears that **as few as 20% of infected people actually exhibit any symptoms**, we must all take responsibility for the protection of ourselves and others. It is a sensible precaution therefore to wear a face-covering in any situation where distancing is not possible, or where the risk of infection is increased due to other factors.

Wear a face covering;

- **on public transport***
- **when attending hospital for an outpatient appointment***
- **in any healthcare setting**
- **when donating blood**
- **in supermarkets and other shops***
- **at the hairdresser / barber**
- **in any public place, indoors or outdoors, where social distancing is not possible**

** now mandatory in some parts of the UK*

HOW TO WEAR A NON-MEDICAL FABRIC MASK SAFELY

[who.int/epi-win](https://www.who.int/epi-win)

Do's →



Clean your hands before touching the mask



Inspect the mask for damage or if dirty



Adjust the mask to your face without leaving gaps on the sides



Cover your mouth, nose, and chin



Avoid touching the mask



Clean your hands before removing the mask



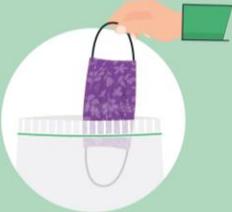
Remove the mask by the straps behind the ears or head



Pull the mask away from your face



Store the mask in a clean plastic, resealable bag if it is not dirty or wet and you plan to re-use it



Remove the mask by the straps when taking it out of the bag



Wash the mask in soap or detergent, preferably with hot water, at least once a day



Clean your hands after removing the mask

Don'ts →



Do not use a mask that looks damaged



Do not wear a loose mask



Do not wear the mask under the nose



Do not remove the mask where there are people within 1 metre



Do not use a mask that is difficult to breathe through



Do not wear a dirty or wet mask



Do not share your mask with others

In addition to wearing your mask correctly, you must also remember to wash or sanitize your hands thoroughly and regularly, and maintain distance from others of at least one metre, and **two metres wherever possible**

Lynn Howarth cycled every day during May, raising £1,325



Like most people I had never heard of Guillain-Barré syndrome until my dad had it in 2015-2016, where he spent 163 days in ICU completely paralysed and on a ventilator, then 7 months in neuro-rehab learning to do everything again. Today I cycled 33 miles from my dad's house to Dave's in Morecambe for the fundraiser **#GAINmomentum**. Dad and Dave both had GBS in 2015 and ended up in neighbouring beds in rehab. My dad had AMAN and Dave had AMSAN, whilst my dad made a full recovery, Dave is still in a wheelchair and has limited use of his hands. Unfortunately, under lockdown rules his physios can't enter the house and carry on their work with his recovery. I told both men, when I started this fundraising lark, that I would cycle door-to-door from my dad's to Dave's and today was the perfect day for it.



Left and centre: Lizzie in April 2019 and following recovery from GBS



Above: Fellow planker Laura McKenzie-Wynne, joining in from Hong Kong

My name is Lizzie, and I'm a 4th year medical student at Nottingham. This time last year I developed Guillain-Barré syndrome (GBS), a rare autoimmune condition where the immune system attacks the nervous system causing paralysis. It left me unable to move, feel, breathe, swallow, speak or see, and relying on a ventilator to breathe. Amazingly, over months to years, most people (including myself) make a good recovery. However, it is a terrifying, isolating & painful journey in which patients suffer much indignity & uncertainty.

I've always enjoyed exercise, but experiencing paralysis has given me a new perspective on what a privilege it is to be able to move. Myself and my brilliant personal trainer Rebecca (S.C.U.L.P.T) have set up a "plank challenge" to do a plank a day for the month to raise money for GAIN, raise awareness of GBS & signify the difference a year can make in these uncertain times. We're aiming to get a collective team total of 24hrs plank time over the month!

Lizzie and friends raised £1,251 with their plank challenge

My Grandad contracted GBS (Guillain-Barré syndrome) in 2011. It is a rare and terrifying disorder in which your body's immune system attacks your nerves and it paralysed my Grandad within 'one' day. It was a long road to recovery and has left him with long term effects including being unable to cycle which was something he loved to do.

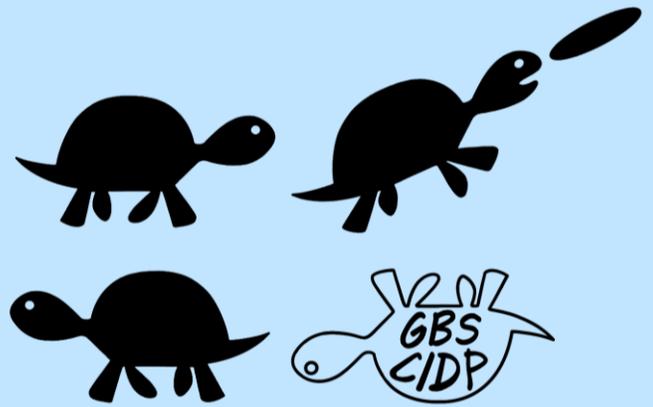
On Saturday 16th May I'm going to cycle a marathon distance to raise awareness for GAIN, the charity which helps people with GBS, followed by another marathon ride on Sunday 17th May!

Jack raised awareness in his community, plus a total of £535 through his double marathon challenge



May is Guillain-Barré syndrome and CIDP awareness month, and this year, despite lockdown, dozens of you took up the challenge to get moving, get fit, and spread the word!

Here are the stories behind a few of you who took part in our first annual GAINmomentum challenge



#GAINmomentum

10 Miles for #GAINMomentum

Lovely socially distanced run for the GAIN charity, great to see so many familiar faces out and about too.



Distance	Avg Pace
10.51 mi	12:40 /mi
Moving Time	Elevation Gain
2:13:10	240 ft
Calories	Avg Heart Rate
2,100 Cal	166 bpm



Sarah James and friends spread the word and smashed their fundraising target, raising £412

What can I say? Other than a heartfelt thank you to everyone. Those who donated, shared and supported. Topped off by a surprise socially distanced support crew who joined in, we passed, or we called in on. Target smashed, 10 miles run and £400+ going to a great little charity #GAINmomentum. Thank you!

Sarah with her dad, (top right) and challenge companions



Sarah Clements and 14 friends set themselves a challenge to for GAIN momentum to run 1,000 km in total during May.

There were 3 runners in London pounding the empty lockdown streets and along the Thames. The rest were in the Surrey Hills, following each other's trails of painted tortoises as they weren't able to run together as a group.

All wore their special edition green GAIN momentum T-shirts to **help raise awareness** of the charity and Guillain-Barre syndrome. Sharing photos and keeping a log of their progress helped to keep them motivated and they finished the month on a challenge-busting combined total of 1611 km (or 1001 miles). Now able to run together as a group again (or at least 6 of them can) they continue to run wearing their GAIN T shirts and are already talking about repeating it next year.



Kim Richards, with her husband Rob, and children Olivia and Harry, set themselves a family challenge to walk 250 miles between them during May.

'We are raising money for GAIN as this is a charity close to our hearts. Rob was very lucky to survive GBS in 2014 and is left with very little after-effects. Not everyone is so lucky, and this amazing charity is there to support those people'

The Richards family walking challenge raised £140

Josh Wing set himself a challenge to start getting back to pre-GBS levels of fitness, raising funds, and awareness amongst friends and family, at the same time.

'So that's #GAINmomentum complete!

Proud to have been part of #gbsawarenessmonth! Various workouts, weightlifting sessions and almost 400 sit-ups later!

I've still got a long way to go but happy with my personal progress and will continue my challenges! Thank you to all my friends that have donated to @gaincharity and helped spread the word this month!



'In January 2020 mine and my family's lives were turned upside down by this awful illness. This illness affects people in many different ways. I am fortunate to be able to walk again let alone run. I am going to complete this challenge of walking/running 5K by the end of May 2020, not just for myself but for everyone who is suffering and for this charity who provides support and information to people when they are at their most vulnerable.

I had GBS in January 2020 as a result from Glandular fever. I went downhill fast with being able to walk with help into hospital then within a day not being able to walk at all. I still had use of my hands, but they were very weak. I was admitted to hospital then had lumbar puncture, blood tests and MRI within two days started IVIG treatment. After two weeks I went home walking with a frame after working with physios. At home I continued the exercises i was given whilst waiting for community physios. From there I built up my strength to walk on my own and within weeks able to climb the stairs on my own. After 3 months I returned to work part time and from then I have continued to build on the exercise I can do, I still get tired and nerve pains in my feet at times but for me the exercise is the key to get me back to me. I really enjoyed doing this challenge and I am continuing my running now. '

Nicola Doublet completed her challenge and raised £380



Stephen and Barbara Chambers walked and ran their way to raising £375

In January 2016 Steve went from being a fit healthy marathon runner to someone who was unable to stand or walk. He was numb from his toes to his chest and the illness affected most of his major organs. He was diagnosed with GBS but following a relapse, many painful invasive tests the diagnosis was changed to CIDP. Although he can now walk and run (short distances) and may appear very well he suffers daily with very painful neuropathic feet and hands and chronic fatigue, there are no two days the same. GAIN charity has helped us with advice and support when we really needed it.

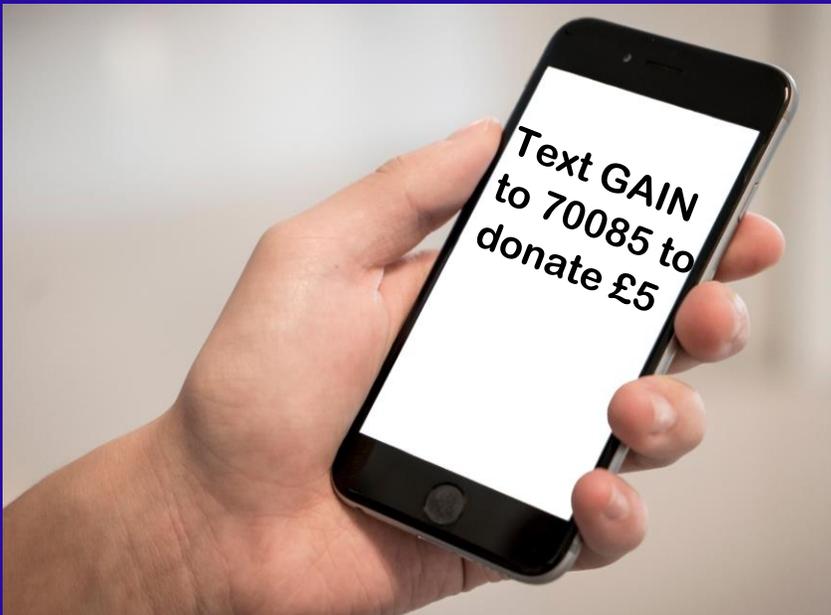
Throughout the month of May Steve and I will be undertaking the GAIN momentum challenge. Between us we will try and walk/run 100 miles.



Once again, we're blown away by the imagination and determination of our members and supporters in rising to the challenge. Although primarily to raise awareness and to get people moving, we're delighted to announce that our first annual #GAINmomentum campaign also raised more than £5.5K! Join us next May and see what you can achieve!



Announcing the launch of our brand new Text Giving campaign



We like to make it as easy as possible for you to support your favourite charity, so have signed up with Donr, the Text Giving service that offers charities an affordable and flexible platform with no monthly, keyword or set-up fees.

Not only that, but we get all the Gift Aid on eligible donations!

Example:

Donation amount	£5.00
Eligible for 25% Gift Aid?	£1.25
Minus 5% fee	£0.25
Donation worth	£6.00

We currently have two campaigns in place, allowing our supporters the choice of making either a one-off or a regular monthly donation.

To make a one-off donation

Text GAIN to 70085 to donate £5
(or add your own amount, e.g. GAIN10)

To make a regular monthly donation

Text GAINAGAIN to 70085 to donate £2 per month
(or add your own amount, e.g. GAINAGAIN5)

Because we can have an unlimited number of campaigns running concurrently, we can give our fundraisers their very own keyword campaign code!

If you are busy raising funds to help us through this most difficult of times, and would like to encourage donations from your supporters through a personalised campaign keyword, get in touch and we'll set one up, just for you. You can then share it across social media platforms and amongst friends, family and colleagues, and even advertise it in your wider community with posters and flyers!



Returning to work 'after' Guillain-Barré syndrome

Developing Guillain-Barré syndrome means everything grinds to a halt for a while. **Andy Ingham** tells us about returning to work as he started to get his life back.

It's a funny old world. One day I'm living my life as usual, juggling home and work life, having seemingly endless energy levels and thinking nothing of it. Then the next day I get pins and needles in my hands and feet and a couple of days later I'm in hospital paralysed from the neck down. Following a barrage of tests, I'm diagnosed with this strange thing called GBS (AMAN variety). This was in January 2019 and in the run up I had been suffering from food poisoning.

The purpose of this short account is to focus on my return to the 'normality' of work, so I won't dwell on the two and a half months I spent in hospitals and the treatments involved... I am a volunteer with GAIN so if you or a member of your family are affected by GBS and want to talk about your experience then please ask GAIN to put you in touch. It's always good to share!

Whilst I was in recovery mode I stayed in contact with my employer and we were able to agree a return to work plan. This included a couple of measures to help with my fatigue and other residuals; a phased return starting with a few hours a week and then building up to a full week over a period of time. Being able to work from home was a big help as travelling on public transport was very tiring. During this period, I was able to work on specific tasks and this helped me settle back into work life. My employer also provided access to a wellbeing counsellor and I found it helpful to talk to someone about my experiences.

So how were the first couple of months? Difficult! I took part in lots of conference calls and I found that my levels of concentration drifted and my memory skills were somewhat lacking; the quality of my handwriting was poor (not that it was ever neat!) and using the keyboard was an effort as my hands weren't that flexible. I had to have lots of breaks so that my legs didn't seize up.

That said, it was great to talk to colleagues and catch up on what they'd been up to over the last year and it gave me the opportunity to push GBS off centre stage for a while each day and let me focus on other things. Overall, I appreciate the support that I've received from my wife and family during this period and that of my employer and line manager in helping me settle back into 'normal' life.

But then came along COVID-19 and a whole new set of challenges...



In sickness and in health; Andy on his wedding day, originally meant to take place in February 2019, but postponed until December of the same year.

Have you recovered from COVID-19?



Plasma from people who have recovered from COVID-19 may save the lives of people who are still ill.

The NHS is leading a programme to collect plasma to help with national clinical trials. Two clinical trials are underway to confirm the safety and effectiveness of these transfusions. The trials are also exploring other treatments for people with COVID-19.

As part of these trials the NHS are:

- collecting plasma from people who've had COVID-19
- managing the convalescent plasma aspects of the trials, including hospital set up and staff training

What is convalescent plasma?

Plasma is a yellow-ish liquid in your blood that carries red and white blood cells and platelets around the body. After a virus, your plasma contains antibodies used to help fight infection.

Convalescent plasma is the antibody-rich plasma of someone who has recovered from a virus, in this case COVID-19.

Why is convalescent plasma important?

Plasma from people who've had COVID-19 may contain antibodies that their immune systems have produced in fighting the virus. This plasma can be transfused to patients whose immune systems are struggling to develop their own antibodies.

The NHS will use donations from people that have a high level of these antibodies in the trials.

Could you donate plasma?

If you have tested positive for coronavirus or had clear symptoms you can register your interest in becoming a plasma donor.

Not everyone is able to donate plasma for these trials. This is because there are strict criteria for donors based on health, age and lifestyle factors as well as 'on the day' reasons like vein suitability.

If you would like to know more, please visit the NHS website link below;

<https://www.nhsbt.nhs.uk/covid-19-research/plasma-donors/who-can-donate-plasma/>

OCTOBER 2020

MO	TU	WE	TH	FR	SA	SU
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

A date for your diary

The AGM is going ahead on Saturday, 17th October, but will be held via our **StarLeaf** video conferencing system, instead of at Head Office.

This means that anyone can attend, wherever you are in the UK or Ireland.

If you are a voting member of GAIN, make sure you have renewed your membership this year, and look out for your voting slips from the end of September.

A link allowing you to join will be on the website.

Speaking of StarLeaf...

Many of you be aware that our local branch meetings, also known as 'gain2gethers' have been cancelled for at least the remainder of 2020.

Although face-to-face gatherings are off the agenda for now, this doesn't mean you can't get together for a chat. If you are someone who enjoys sharing support and advice with others who have been affected by GBS, CIDP or one of the variant conditions, why not set up a virtual branch meeting using our StarLeaf app?

Decide on a date and time, and email us at office@gaincharity.org.uk or phone us on 01529 469910 during office hours (Monday to Friday between 9am and 3pm). We'll set it up and send out invitations by email so other branch members know about the chance to get reconnected.

Don't forget, we also hold a weekly chat every Tuesday at 2pm. Come and join us!

<https://gaincharity.org.uk/virtual-branch-meetings/>



No. 1

Keep collecting those crisp packets!

We're still taking in crisp packets, for Terracycle to recycle in exchange for cash, so please keep them coming.

If you live near enough to drop them off, please leave them in the big pink bin outside the front of our office in Sleaford. If you live further away, please collect at least 6 kilos of crisp packets, and then contact us to request a courier label that you can attach to the box and have it picked up, free of charge.

Please do not post them to us using our freepost address, FREEPOST GAIN, as we will be charged more than the value of the crisp packets inside.



No. 2

Sell unwanted DVDs, and books on Ziffit

Want to help, but a bit strapped for cash? Got a cupboard or bookcase full of books or DVDs that you don't want anymore?

We've signed up to an initiative run by Virgin Money Giving in partnership with Ziffit, so you can turn your unwanted books, CDs, DVDs and console games into donations to your favourite charity.

Download the app or visit **ziffit.com**



4 easy ways to help

No. 3

Have a clear out & sell your stuff on eBay

If you have been using lockdown to have a good clear-out, you might now find yourself surrounded by bags of old, unwanted stuff.

It's amazing what you can sell on eBay, but did you know that you can choose to donate some or even all of the proceeds to your favourite charity?

You might even increase the chance of your items selling because items that benefit charities can sell faster, even at a premium price. Donate 10% or more and your item will feature an attention-grabbing charity ribbon—it may even be listed in the Charity Shop. Plus, you reduce your seller fees and enjoy tax savings. Happy days!



No.4

Set up a birthday fundraiser on Facebook

Create a fundraiser for a cause that's important to you. It's easy to set up, and Facebook can even give you tips to reach your goal.

The donations come straight to GAIN, so you don't have to do anything more than share your fundraiser with your friends and family, and ask them to donate to your favourite charity in lieu of a birthday gift.

https://www.facebook.com/fundraisers?birthday&source=help_center_how_to_create_birthday_fundraiser



As the COVID-19 pandemic sweeps across the globe, many neurologic specialists have been on the lookout for potentially serious nervous system complications such as Guillain-Barré syndrome.

Though Guillain-Barré syndrome is rare, it is well known to emerge following bacterial infections, such as *Campylobacter jejuni*, a common cause of food poisoning, and a multitude of viral infections including the flu virus, Zika virus and other coronaviruses.

Studies showed an increase in Guillain-Barré syndrome cases following the 2009 H1N1 flu pandemic, suggesting a possible connection. The presumed cause for this link is that the body's own immune response to fight the infection turns on itself and attacks the peripheral nerves.

Guillain-Barré syndrome & pandemics

This is called an “autoimmune” condition. When a pandemic affects as many people as the current COVID-19 crisis, even a rare complication can become a significant public health problem. That is especially true for one that causes neurological dysfunction where the recovery takes a long time and may be incomplete.

The first reports of Guillain-Barré syndrome in COVID-19 pandemic originated from Italy, Spain and China.

Though there is clear clinical suspicion that COVID-19 can lead to Guillain-Barré syndrome, many important questions remain. What are the chances that someone gets Guillain-Barré syndrome during or following a COVID-19 infection? Does Guillain-Barré syndrome happen more often in those who have been infected with COVID-19 compared to other types of infections, such as the flu?

The only way to get answers is through a prospective study where doctors perform systematic surveillance and collect data on a large group of patients. There are ongoing large research consortia hard at work to figure out answers to these questions.

Understanding the association between COVID-19 and Guillain-Barré syndrome

While large research studies are underway, overall it appears that Guillain-Barré syndrome is a rare but serious phenomenon possibly linked to COVID-19. Given that more than 10.7* million cases have been reported for COVID-19, there have been 10** reported cases of COVID-19 patients with Guillain-Barré syndrome so far.

It is certainly possible that there are other cases that have not been reported. The Global Consortium Study of Neurological Dysfunctions in COVID-19 is actively underway to find out how often neurological problems like Guillain-Barré syndrome is seen in hospitalized COVID-19 patients.

Also, just because Guillain-Barré syndrome occurs in a patient diagnosed with COVID-19, that does not imply that it was caused by the virus; this still may be a coincident occurrence. More research is needed to understand how the two events are related.

Due to the pandemic and infection-containment considerations, diagnostic tests, such as a nerve conduction study that used to be routine for patients with suspected Guillain-Barré syndrome, are more difficult to do. In both U.S. cases, the initial diagnosis and treatment were all based on clinical examination by neurological experts rather than any tests. Both patients survived but with significant residual weakness at the time these case reports came out, but that is not uncommon for Guillain-Barré syndrome patients. Though the reported cases of Guillain-Barre Syndrome so far all have severe symptoms, this is not uncommon in a pandemic situation where the less sick patients may stay home and not present for medical care for fear of being exposed to the virus. This may skew our current detection of Guillain-Barré syndrome cases toward the sicker patients who have to go to a hospital.

*10.7 million cases worldwide as of 2nd July 2020

**The Lancet reported 19 cases of GBS July 2020

Membership renewal



Thank you to everyone who has already sent back their membership renewal form, or has confirmed renewal via phone or email. Thanks also to the 321 of you who attached a stamp, instead of using the Freepost GAIN address. Every renewal that has a stamp attached, or that comes in by phone or email saves the charity 63p!

If you are using the Freepost address to return your form, please make sure you only write the words **Freepost GAIN**, and nothing else. If you include our office address as well as the Freepost GAIN address, and don't attach a stamp, the charity is charged £2.00 as a 'no postage paid' fee.

No stamp, Freepost GAIN plus office address

Royal Mail charge = £2.00

No stamp, Freepost GAIN

Royal Mail charge = £0.63

Attaching a stamp, plus office address,
OR email confirmation, OR phone call

Royal Mail charge = £0.00

If you wish to vote in the AGM this October, you must update your Voting Member membership in order to receive your voting slips, which will be sent out at the end of September / beginning of October.

A word about Gift Aid

We love Gift Aid. It costs you nothing, but gives charities an extra 25% on every eligible donation, courtesy of HMRC. If you aren't eligible for Gift Aid yourself, but your partner, or another household member is, please consider amending your membership profile to their name, not forgetting to have them make a Gift Aid declaration.

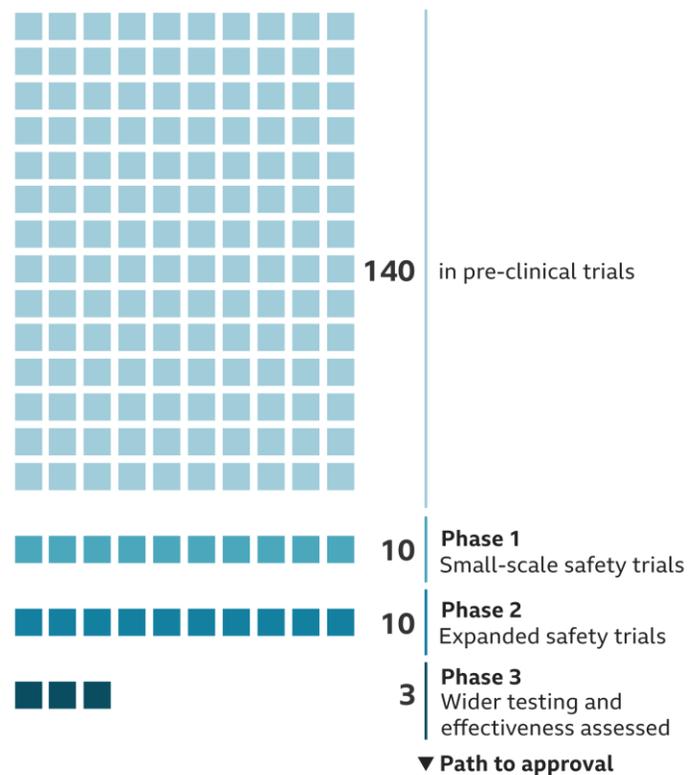
UK secures strong portfolio of promising COVID-19 vaccines

The UK government has now secured access to vaccines that use three completely different approaches:

- 100m doses of the Oxford vaccine made from a genetically engineered virus
- 30 million doses of the BioNtech/Pfizer vaccine, which injects part of the coronavirus' genetic code
- 60 million doses of the Valneva, which uses an inactive version of the coronavirus

Using different styles of vaccine maximises the chance that one of them will work, but Kate Bingham, chair of the UK government's Vaccine Taskforce, urged against complacency; "The fact remains we may never get a vaccine and if we do get one, we have to be prepared that it may not be a vaccine which prevents getting the virus, but rather one that reduces symptoms."

How many vaccines are being tested?



Source: WHO, 15 July

BBC

Want to get involved? You can sign up to be contacted for coronavirus vaccine studies; <https://www.nhs.uk/sign-up-to-be-contacted-for-research>

Raise FREE donations for **GAIN**

every time you shop online

<https://www.easyfundraising.org.uk/causes/gaincharity/>



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As easy as 1,2,3!

1. Join GoRaise

Click on Join to add a few details and start supporting GAIN

2. Go shopping!

Search on GoRaise for the retailer or product that you want, and click out. It's that easy.

3. Raise money for free

Shop as normal and the retailer donates a portion of your spend to us. You don't pay a penny extra.

<https://www.goraise.co.uk/GAIN/?refid=7253>



Go somewhere amazing!

Discover the hidden gems waiting for you across the British Isles - stunning coasts, beautiful countryside and historic cities.

You can book your trip with top travel brands via Give as you Live Online - find great deals on cottages, hotels and more.

And even better, you can raise a free donation for Guillain Barré & Associated Inflammatory Neuropathies (GAIN).

<https://www.giveasyoulive.com/charity/gain-charity>

Christmas 2020

What better time to think about Christmas than the height of summer? Get ahead of the game with our range of charity Christmas cards, with 10 brand new designs for 2020. Show your family and friends that you're thinking about them this Christmas, secure in the knowledge that you are helping people affected by GBS, CIDP and the variants. Sold in packs of 10 cards measuring 150mm x 150mm, with the message 'With Best Wishes for Christmas and the New Year' on the inside. The reverse of each card includes information about the charity and conditions. All designs cost £3.50 and can be ordered via the GAIN website, www.gaincharity.org.uk or by phoning 01529 469910 during office hours.



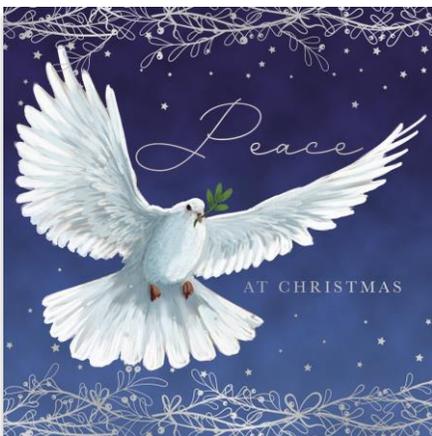
Snowman Trio
(on textured board)



Holly and Ivy Bauble
(textured board with red foil detail)



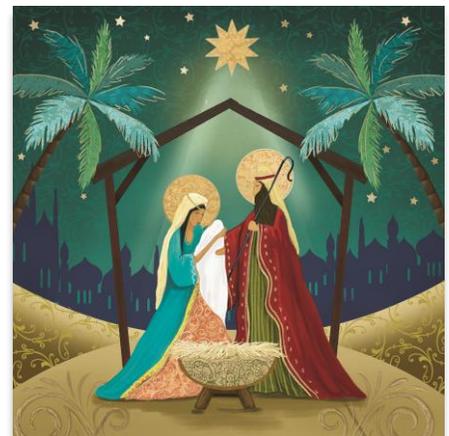
Winter Wreath
(with glitter detail)



Dove in the Night Sky
(with silver foil detail)



Robin and Berry Branch
(on textured board)



Mary and Joseph
(with gold foil detail)



Cute Dog



Santa with Robin



Sending Christmas Greetings



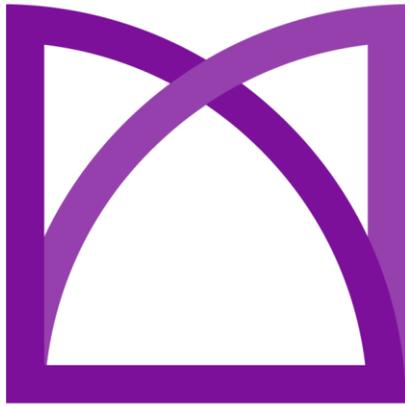
Merry Christmas Baubles
(textured board and gold foil detail)



Gift wrap 'Winter Wraps'
4 sheets plus 8 tags (2 designs) £3.50



Gift wrap 'Robin Wraps'
4 sheets plus 8 tags
(2 designs) £3.50



McClure
SOLICITORS

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 both to you and to GAIN and carries no obligation.



Why do you need a Will?

You already know that every adult should have a Will. Without a Will the law decides who inherits, but with a Will, you decide.

Why should you do it now?

No-one knows what is around the corner. If you leave it until you need it, it will be too late.

There is no obligation to make a donation or leave a legacy to GAIN, 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.

McClure has offices throughout the UK, but if there isn't one in your area, they can come to you. It really couldn't be easier, so why not arrange a free consultation today!

Tel 0800 852 1999



<https://www.mcclure-solicitors.co.uk/wills>