



Newsletter issue 18 / 27 August 2021

Back to school

Guidance for returning to school differs across the UK and Ireland. If you have children of school age, please check the current advice for where you live to make sure you are prepared for the start of the new school year.

England: www.gov.uk

Scotland: www.gov.scot

Wales: www.gov.wales

Northern Ireland: www.nidirect.gov.uk

Republic of Ireland: www.gov.ie



Team GB Paralympian cyclist, Ben Watson, battled GBS aged 14

In 2003 Ben was diagnosed with Guillain-Barré syndrome, causing him to lose control of his legs, as well as residual weakness in other areas.

"I was paralysed in hospital for a couple of months, then I came out of hospital and endured physio. I was in a wheelchair for 9 months and crutches for 18 months after that. So effectively I had to learn to walk again, and I've been left with weakness in my hands. Below my knees I don't have much movement, sensation, control, or circulation either," he says. This meant he could no longer play football or rugby so found himself borrowing a mountain bike from a friend.

"Mountain biking was just something I did all the way through university, and I never even thought about parasport as an option."

However, in 2016 after the Rio Olympics, British Cycling held a talent ID Day where a friend encouraged him to go along to this to see what may come of it.

The session was a success for Ben as he was then brought into the academy in which he was classified as a C3 rider. This will be Ben's first time competing at a Paralympic event. "The last five years of hard work are now paying off and I still don't think it's really sunk in and it's so awesome to get that phone call saying you are going to the games.

"We fly to Tokyo on 23 August, I compete in the **time trial on 31 August** and then the **road race on 2 September**.

"I'm in the best place I could be for the games and I'm really looking forward to get out there, do my best and enjoy myself," he says.

Full story here: <https://www.questmedianetwork.co.uk/news/sport/the-glossop-cyclist-who-is-preparing-for-his-first-paralympic-games/>



Photo: British Cycling



GAIN 200 Club

Winning numbers for August;

54 108 11

New members wishing to join in time for the September draw, must register via the GAIN website or by phoning the office before noon on Wednesday 8th September (contact details on back page). Open to residents of England, Scotland and Wales who are 16 or over. See website for full terms and conditions;

<https://gaincharity.org.uk/product/gain-200-club/>

Ben is the only member of Team GB that we know of whose Paralympic journey started with Guillain-Barré syndrome, but he isn't the only Paralympian to look out for! Let's also get behind GBS survivors, Peter Pal Kiss (Hungarian Paralympic canoeist), Juan Perez Gonzalez (Spanish Paralympic table tennis player), and Australian Paralympic swimmer Rachael Watson, World Record holder and Rio 2016 Gold Medallist!



Could YOU be a plasma donor?

Immunoglobulins, administered in the first few weeks of an attack of acute Guillain-Barré syndrome, or as an ongoing treatment for people with CIDP, can play a vital role in the management of these debilitating conditions.

As of April 2021, people in the UK can donate plasma, and the plasma donated will be used to manufacture life-saving products such as immunoglobulins to treat NHS patients.

There is currently a shortage of immunoglobulins here in the UK, so if you can, please donate your plasma so patients can continue to access this life-saving product.

**To find out more, visit;
blood.co.uk/plasma
 or call 0300 123 23 23**

Consulting on a National Care Service

The Independent Review of Adult Social Care recommended the creation of a **National Care Service in Scotland**, with Ministers being accountable for adult social care support.

The Scottish Government hopes to go further, and has opened a consultation seeking views on creating a comprehensive community health and social care service that supports people of all ages. They are proposing that the National Care Service will define the strategic direction and quality standards for community health and social care in Scotland. It will have local delivery boards which work with the NHS, local authorities, and the third and independent sectors to plan, commission and deliver the support and services that the people of Scotland require.

You can register to attend the virtual engagement events, and complete an online consultation form; <https://consult.gov.scot/health-and-social-care/a-national-care-service-for-scotland/>

Consultation closes on 18 October 2021

Source: <https://www.independentliving.co.uk>

Make sure you get your flu jab this autumn

Experts have warned the NHS needs to prepare for a harsh winter, as a report shows that as many as 60,000 people could risk dying from flu.



The report, from the Academy of Medical Sciences, said that a mix of COVID-19, flu and respiratory syncytial virus (RSV), could put severe strain on the NHS in winter.

Experts explained that, if left unchecked, the flu season could be particularly deadly, with statistics from the report predicting that there could be almost double the hospital admissions and deaths compared to a 'normal' year - meaning between 15,000 and 60,000 people could be at risk of dying.

Measures could be put in place to help mitigate the risks, including an enhanced flu jab programme and rapid testing. A widespread flu vaccination campaign is also taking place this year for over-50s. The report stated that there were still high levels of uncertainty about how much it would affect the health service.

Lockdowns in place throughout 2020 meant a lot of respiratory viruses were kept away, but concerns over population immunity have since been raised as a result. With over five million already on the waiting list, there could potentially be an ongoing backlog of care for the NHS, alongside staff shortages and reduced bed capacity.

Source: Emma Soteriou, published by LBC on 15 July 2021

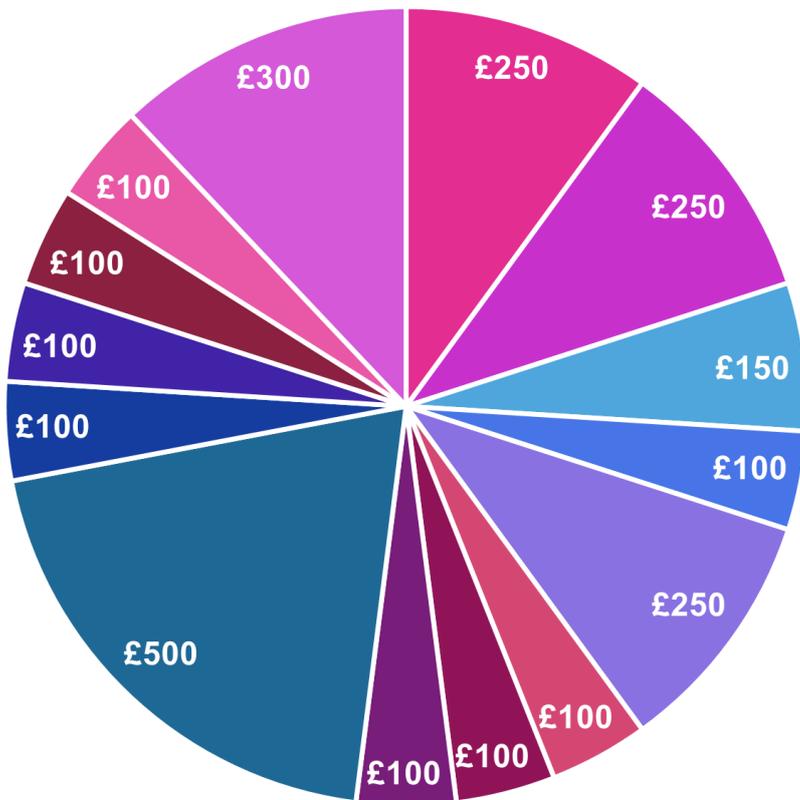
If you are in an 'at risk' group from flu, then our advice here at GAIN is to get your flu jab.

GBS does not relapse, and a recurrence is exceptionally rare. A vaccine causing GBS for a second time in someone who has had GBS before is not something we come across here at the charity, and there is no scientific evidence to support the theory that a vaccination will trigger a second GBS episode. For those of you who are living with CIDP, you already have it, and you can't get a double dose. If your CIDP is being treated with corticosteroids, such as Prednisolone, then you have a suppressed immune system, and you should take extra care in protecting yourself from infection by taking all recommended vaccinations.

theBigGive

30 Nov – 7 Dec 2021

Big News!!! Following our appeal in last month's newsletter, and on our website and social media channels, we are delighted to announce that we have met our pledge target of £2,500!



Heartfelt thanks go to our wonderful Pledgers for getting us to the next stage of the campaign! ♥

£250 Ed Borgars
£250 Richard in South Norfolk
£150 Richard in Lincolnshire
£100 Richard 'Chris' Kierstenson
£250 Paul in Dorset
£100 Stephen in Twickenham
£100 Carol
£100 Yvonne Hewitt
£500 Anonymous
£100 David & Maureen in Burbage, Leics
£100 David in Cwmbran, Torfaen
£100 Julie Wilson
£100 Marc
£300 Jackie Richardson

What happens next?

Pledging plays an important part in getting the campaign off the ground, but without donations, there will be nothing to match fund, so don't worry if you weren't able to be a Pledger - for the campaign to be successful, we need donors too!

With pledges totalling £2,500 secured from our own supporter base, we hope to attract an equal amount of match funding from The Big Give Champions, at least two of which have a keen interest in health-related charities. If we are successful, then donations made to the appeal during the campaign week will be worth double!

Once The Big Give Christmas Appeal 2021 is launched on 30 November (Giving Tuesday), and throughout the campaign, we will be inviting **online donations** from anyone who hasn't pledged. As long as you can donate online, you can take part and help us reach our campaign target of **£10,000**.

If you would like to make a donation between now and Christmas, please consider making it during The Big Give Christmas Appeal week so you can DOUBLE your donation!

Further details of how to join in the campaign will be available here in the newsletter and via the website and social media channels in the run-up to the campaign, so WATCH THIS SPACE and help us reach our £10,000 campaign target!

Note for your diary; to double your donation, donate online to The Big Give Christmas Appeal between 30 Nov to 7 Dec 2021.



Don't pay a premium for free DVLA services

DVLA is urging motorists to beware of websites that charge a premium for DVLA online services that are cheaper or free on GOV.UK. The agency is reminding motorists that they should always use GOV.UK, to be sure they are dealing directly with DVLA and not paying more than they need to.

Guy Anker, deputy editor at MoneySavingExpert.com, advises:

"These copycat sites aren't illegal, but they dress up like legitimate webpages, and use clever tricks to appear higher on search engines. They get you to fill in forms, which requires no more work on your part than if you'd done it yourself via the official sites, and then they overcharge you for 'administration' or 'services' – which is really just passing it to the relevant body, with no extra work involved. These services are usually free or much cheaper if you do it yourself"

"The obvious red flag that you're on a copycat site is if you're being charged for something that's usually free – such as updating your vehicle logbook (V5C) when you've changed your address. Another tell-tale sign is the web address, so if you should be on a government website, carefully inspect it to make sure it says GOV.UK. It's also worth knowing the true price of a paid-for service – in the past we've spotted firms offering 'checking services' for driving licence renewals at a cost of £60, more than four times the £14 it costs to do it through GOV.UK."

DVLA has been contacted more than 1,200 times* since January 2020 by customers who have paid more for services than they need to by using unaffiliated websites.

**as of June 2021*



Get connected – grab a cuppa and join a video chat!

Open forum	Lancashire & Cumbria	GBS / acute	CIDP / chronic
2 nd Tuesday of the month at 2pm	1 st Friday of the month at 2pm	3 rd Thursday of the month at 2pm	4 th Thursday of the month at 2pm

For details of how to join a video chat, visit www.gaincharity.org.uk

A massive thank you to everyone who continues to support us during these difficult times. If you would like to make a donation, please visit the website and click on the DONATE button, or simply text GAIN to 70085 to donate £5

Keep in touch

Look us up on social media

-  office@gaincharity.org.uk
-  www.facebook.com/groups/727400487277814/
-  @gaincharity
-  gaincharity

Contact us during office hours (Mon-Fri 9am-3pm)

Email: office@gaincharity.org.uk

Phone: 01529 469910

Helpline: 0800 374803 (UK) / 1800806152 (RoI)

**And if you want to drop us a line, you can write to us at the usual address;
GAIN, Glennys Sanders House
Pride Parkway, Sleaford, NG34 8GL**