

# Guillain-Barré & Associated Inflammatory Neuropathies



Welcome to newsletter **issue 10 / September 2020**

We took a short break from the newsletter over the summer, as the charity's magazine, **gain4all** was due to hit the doormats. It's hard to believe that autumn is here, and schools are opening their doors for the first time in over five months for the majority of children. That means flu season is just around the corner, and this year more than ever, the most vulnerable need to consider protecting themselves with a flu vaccination. Although most of us have by now regained an element of freedom (unless unlucky enough to be caught in a localised lockdown), the risk of COVID-19 hasn't gone away, so to keep ourselves and each other safe, it is likely that we will all have to adapt to the 'new normal' of face-coverings and social distancing for some months to come. See below for online links to current guidance across the UK and Ireland.



## Changes to crisp packet recycling scheme

We have some bad news about the crisp packet recycling scheme that has earned the charity almost £800 since we joined in Spring 2019.

To keep costs down, Terracycle has recently changed the rules regarding the number of shipments and maximum weight for which we can earn points. We will now only receive points for one shipment per month, weighing no more than 20kg, which equates to 2000 points (£20). This means we can no longer offer free courier labels to third party collectors sending >6kg.

As well as the fundraising element, a major benefit of the scheme is raising awareness of the conditions and charity, and we would of course be grateful to anyone still wishing to send us their crisp packets. Collectors can therefore still post or courier their crisp packets to us to go towards the monthly shipment we are allowed, but this does incur a cost to the sender.

The most cost-effective way to do this that we have found, is using the DPD drop-off service, which allows you to send up to 20kg for £4.79. Anyone within easy reach of the office (NG34 8GL) is of course very welcome to drop them off with us if they are in the area, but we fully understand if neither is an option.

**We would like to thank everyone who has contributed to the scheme to date, and if you are able to keep collecting for us, thank you for your ongoing efforts!**

*NB: We are longer listed for collecting Pringles tubes.*

## COVID-19 stay safe

**Guidance on COVID-19 differs from country to country and is regularly reviewed and updated. Please check the current advice for where you live**

### England

<https://www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance>

### Scotland

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

### Wales

<https://gov.wales/coronavirus>

### Northern Ireland

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

### Republic of Ireland

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



## Re-ordering your repeat prescriptions after 1<sup>st</sup> September

**From 1<sup>st</sup> September 2020, GP surgeries across England will no longer accept repeat prescription requests over the phone.**

This is in line with NHS England and Clinical Commissioning Group guidelines, and is a practice already adopted by many GP surgeries across the country.

Patients on long-term medication who have been approved for repeat prescriptions have a number of options open to them when it comes to re-ordering:

- **Drop off** – put your repeat slip in the box provided at your surgery
- **By Post** – send it to your surgery with a stamped addressed envelope if you want it posted back to you
- **By Fax** (check with your surgery for the number)
- **Online** – there will probably be a link for repeat prescriptions on your GP surgery's website, or you could download the NHS app

### **A guide to ordering a repeat prescription online using an app or website**

If you receive medicine on repeat prescription, you can now use several apps and websites to order your repeats online. You can then collect your medicines from a pharmacy or have them delivered to your home (where available).

When you order a repeat prescription online, you can have your prescription sent electronically to a pharmacy or dispenser of your choice. This means you no longer need to collect a paper prescription from your GP surgery.

If you have not already chosen your regular pharmacy or dispenser (called a "nomination"), some apps and websites allow you to set one up.

If they do not:

- contact the pharmacy or dispenser you want to nominate
- contact your GP surgery to set one up

Ordering a repeat prescription online is now recommended. Due to coronavirus (COVID-19), you may not be able to go into your GP surgery to collect repeat prescriptions.

If you usually get your repeat medicine from your GP surgery's dispensary, or use another dispenser for some specialised items (such as stoma products), you can still order it online.

### **Using apps or websites to order your repeat prescription**

There are apps and websites listed on the NHS website, which work with your GP surgery's computer system. This means you can view and order your repeat prescription online.

Some may also let you see your medical record and book GP appointments.

Further details are available here:

<https://www.nhs.uk/using-the-nhs/nhs-services/pharmacies/how-to-order-repeat-prescriptions-online>

**Once you're set up, re-ordering your repeat prescriptions online or with an app has lots of advantages, but if you aren't too familiar with using electronic services, why not ask a friend or family member who is more confident for some help to get started?**

**And if you're still unsure, there's always the option of dropping off or posting your repeat slip the old-fashioned way.**

# September is Oddfellows Friendship Month



September is Friendship Month, and one of the things that lockdown showed us was just how important our connections with other people are.

## More than 200 years of friendship and support

The Oddfellows was originally set up in 1810 to offer workers and their families insurance should they fall on hard times. Today, the society continues to provide help to its members through difficult periods, with care, welfare and financial support.

## Five top tips to keep connected

- **Telephone** – If you haven't heard from someone for a while, why not give them a ring? If you're short of time, even a text tells them you're thinking about them
- **Postcards** – Letter writing might have fallen out of fashion, but an email or handwritten note only needs to be a few lines.
- **Neighbourhood watch** – When was the last time you talked to your neighbours? You don't need to be the best of friends, even a quick hello over the hedge will help you and them feel more connected.
- **Get online** – You don't just have to use online video conferencing to stay in touch, getting online offers lots of other ways to socialise too. Find your tribe on social media, join an online hobby group, learn with an online course, follow along with an exercise class or join a chatroom.
- **Park life** – Another great way to stay connected is to head to your local park where you could arrange to meet a friend for a socially-distanced walk or picnic.

**Read all about Friendship Month and more;**  
<https://www.independentliving.co.uk/>

**Find out more about The Oddfellows;**  
<https://www.oddfellows.co.uk/events/>

# Staying connected during restricted visiting times

**Since mid-July, hospital visiting has been gradually reintroduced, but restrictions are likely to remain in place for some time to come.**

Policy may differ from one NHS Trust to another, so if you wish to visit someone, it is vital that you check with the hospital first.

Some hospitals allow one named designated visitor only, or a designated visitor plus one essential visitor (such as a parent of a child, or someone who supports a patient with a mental health issue). Many operate a booking system, so you need to telephone ahead and arrange a time slot for your visit.

This is absolutely necessary to keep patients, hospital staff and visitors safe, but restricted access can make an already difficult situation even harder to cope with.

With visits being limited in some cases to once or twice a week (if at all), we need to find other ways to keep in touch and reduce feelings of isolation.

This is where a device such as a smart display can prove invaluable. Smart displays are effectively smart speakers with touch screens attached to them. They offer the same hands-free voice assistant features as smart speakers, letting you play music, check the weather, and control your smart home devices just by talking. But the screen adds a whole new level of information and control on top of that, including watching movies, reading books and video chatting to your friends and family, even if you're not able to meet face to face.



**At only £69.99, the Amazon Alexa Echo Show 8 is one of the best value smart displays on the market**

The GAIN Personal Grant scheme was originally set up to help family members with travel costs incurred by frequent visits during a lengthy hospital stay. Since the COVID-19 pandemic meant hospital visiting was prohibited or restricted, we have also helped families keep in touch by buying them an Alexa Echo Show 8, which is one of the best-value and highly reviewed smart displays on the market. If you, or a close family member is in hospital, why not get in touch and see if we can help?

## Join our weekly get-together

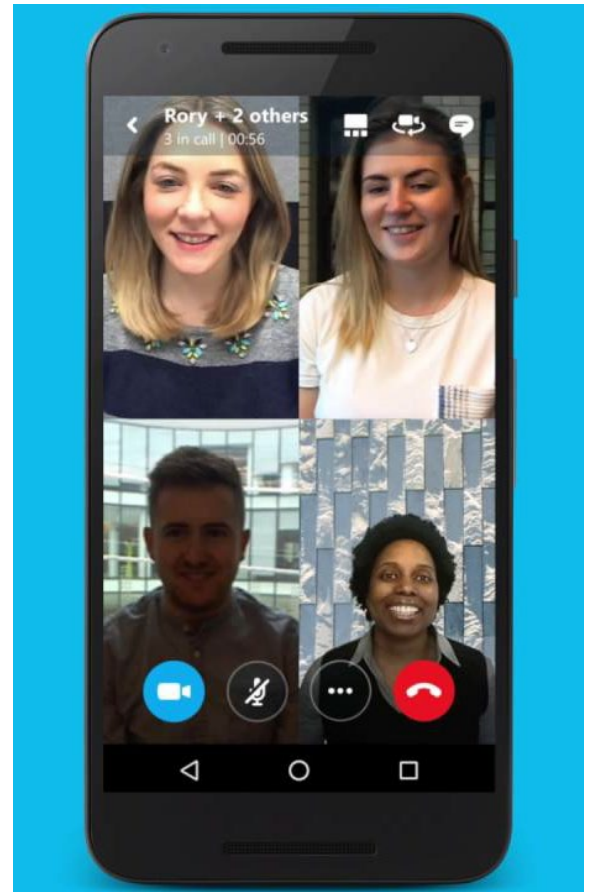
Video calling is as easy as having an actual face-to-face conversation and is almost like being in the same room. WhatsApp, Facetime, Skype and Zoom may be familiar names, but we'd like to introduce you to Starleaf, the app GAIN uses for our **weekly chat**. Wherever you are and whatever device you are on, the StarLeaf app lets you chat to anyone, anywhere. Download Starleaf from your app store, or online via

[www.starleaf.com/products/portfolio/the-starleaf-app/](http://www.starleaf.com/products/portfolio/the-starleaf-app/)

No smartphone or computer? Don't worry! You can't video chat using a landline, but you can still join the conversation using your ordinary phone. Call us to find out how.

**Join the weekly chat every Tuesday at 2pm and connect with other people who understand what it means to be affected by GBS, CIDP and the variants.**

Visit our website for details of how to join in  
[www.gaincharity.org.uk](http://www.gaincharity.org.uk)



**STAY WELL  
THIS WINTER**

**Make sure you  
get your flu  
jab this winter**

**Book yours now**







Getting a flu jab is the most effective way to protect yourself against getting flu and passing it on to others.

This year, anyone getting flu and COVID-19 concurrently could be at a heightened risk. The seasonal flu vaccination programme for 2020/21 is therefore being extended beyond those traditionally considered to be at risk, to minimise the spread and to protect as many people as possible from potentially life-threatening complications. Don't miss out, book now!

<https://gaincharity.org.uk/donate>

## Keep in touch

Look us up on social media

-  [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk)
-  [www.facebook.com/groups/727400487277814/](https://www.facebook.com/groups/727400487277814/)
-  [@gaincharity](https://twitter.com/gaincharity)
-  [gaincharity](https://www.instagram.com/gaincharity)

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

Email: [office@gaincharity.org.uk](mailto: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;

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