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Rich's Update



Well, it seems like I blinked, and January was gone. Maybe I'm getting old, but where does the time go? I think the fact that we have been super busy during January hasn't helped, and I can't quite put my finger on it but things seem to have really picked up at GAIN HQ. The phones and the emails have been hectic, with loads of people seeking input and support. It feels like its been our busiest month to date.

I spent a chunk of the month out on the road, representing the GBS and CIDP Community in parliament (more of that in next month's newsletter) as well as visiting members of the community across the country.

There are huge amounts of work going on at the moment with colleagues from the NHS, and within the community sector, and we will do our best to keep you up to date and make sure your voice is heard. While we try to pop as much as possible in the newsletter, we can't include everything so please keep an eye on our socials as well. You can even find us on Bluesky these days, so please go and give us a follow.

Rich Collins
Chief Executive

Swim Serpentine

We've been promoting a lot of running events recently (and if you're interested in claiming a space at the Brighton Marathon or a Great Run event, check our website!), but we've got one for those who prefer water to tarmac.

We've limited spaces in the sold out Swim Serpentine event this September in London's Hyde Park. You can take a half mile, full mile, or two mile swim across the beautiful lake in the heart of the nations capital. We'll pay for your space, you just need to raise a minimum sponsorship, and taking on a challenge like this, that should be a doddle!

Learn more at gaincharity.org.uk/events, or get in touch via the details on the back of this Newsletter.

Situation in Pune

gaincharity.org.uk/gbs-mass-occurrence-in-pune

A couple of weeks ago, we started seeing a few snippets of information popping up about GBS cases occurring in Pune, India. Most of the alerts were coming up on local news outlets and were referring to an 'outbreak' or 'pandemic.'

We took a closer look and saw report saying that nearly 200 people have been impacted and unfortunately there have been 7 deaths linked to GBS in the area.

There are reports of many people impacted in this mass occurrence testing positive for *Campylobacter* Jejuni, a bacteria that can lead to food poisoning and has been linked to GBS.

Since cases started emerging, visits to the GAIN website have increased by over 1000%. As a result, we felt it best to offer some reassurance.

To those impacted by this awful mass occurrence, we share our heartfelt sympathies. We know how impactful GBS can be, and we wish all those directly impacted a swift and good recovery and pass on our sincerest condolences to those who have been bereaved.

Those not impacted, GBS is not transmissible, and this is a localised incident. This isn't a pandemic of GBS or the start of something global. This is a tragic and rare mass occurrence, the like of which we will hopefully never see again.

Visit to Philadelphia

One of GAIN's amazing volunteers, Jon Follows, was invited to Philadelphia to attend the first Leadership Collaborative Workshop by the GBS | CIDP Foundation International to represent the CIDP community.

"It was rewarding to be in the same room as people who have the same condition as me as we shared a common bond. It was interesting to hear the differences in our symptoms, the care across different countries and what we were now doing to minimise the ongoing condition. The emotional and social impacts, including the impact on our mental health shouldn't be forgotten."



GAIN are over the moon that Jon was able to share his insights with a global community, and can't wait to share his full write up in the next Lowdown.

Changes to IVIg

By the time this arrives, you may have heard word about changes to how IVIg and SCIG is delivered in England from April 2025.

GAIN will be sending out more information shortly and will have online blogs to discuss this. We just wanted to have a closing note in this months newsletter to help assuage any worries you may have.

In short, NHS England has secured new contracts with a list of suppliers. This will improve supply and cost efficiency, meaning better stocks and security for patients. However, this will change some of the brands and products available for your treatment.

While GBS patients shouldn't be impacted, some CIDP and MMN patients may need to switch products. Your clinician will talk to you about it if so. If you do need to change, and the new brand or product doesn't work as well for you as your last one, then they can explore other options from the list. There may also be other options as well.

It can be scary seeing a change in your treatment, but if you have questions talk to your clinician, or reach out to GAIN to chat about it.

Note: At the moment, this change just impacts England, and shouldn't impact the brands in Scotland, Wales, and Northern Ireland.

Get more information at www.gaincharity.org.uk



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