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Suspension of Meetings and Coffee Mornings

We had hoped to resume these from this month but unfortunately Headway House is not available to us. The coffee morning also would be deemed a social event and limited to an attendance of 6 people wearing masks.

Your Management Committee remain active and are working on ways to continue during and after Covid 19 restrictions have ended.

APPG on Epilepsy 2020

WE were privileged to see Baroness Cumberledge give a talk to the All-Party Parliamentary Group albeit in a Zoom presentation on Monday 7th September. She had chaired a review into the adverse effects on foetuses. This had been known for many years but largely ignored until a few years ago. Perhaps this was because of the efficacy of the medications in those unlikely to become pregnant. The tendency to have such deformities as cleft palate or harelip were referred to at a conference in Spain which we attended over 20 years ago. The report on the recent enquiry under the title "First do no harm" made the following recommendations to government

1. An immediate and fulsome apology on behalf of the healthcare system to families affected by Primodos, Sodium Valproate and Mesh.
2. The appointment of an independent patient safety commissioner. They agreed with Baroness Cumberlege that "We do need a new voice, with statutory powers, to talk and act from the perspective

of the patient, to encourage the system to do what needs to be done and hold it to account”.

3. A new independent Redress Agency for those harmed by medicines and medical devices, administered on a non-adversarial process. This had been hoped for and was welcomed, although the details of how it would work needed clarifying.

A cost-of-care-scheme: to allow for discretionary payments to meet the cost of additional needs caused by avoidable harm. The recommendation is that this should be set up promptly given “Patients have waited far too long for redress”.

4. Networks of specialist centres to provide comprehensive treatment: to act as a one stop shop, to signpost and refer patients to other services including educational and, social
5. ***Substantial revision of the MHRA, particularly in relation to adverse event reporting and medical device regulation: The MHRA should demonstrate how patient views have been taken into account and there should be a system-wide healthcare intelligence unit to facilitate early signal detection.***
6. Central, patient-identifiable databases: Publicly searchable database of adverse events for medicines and devices with a dual focus on reporting on device safety and patient reported outcome measures.
7. Transparency of payments made to clinicians. The GMC register to be
8. expanded to include non-financial and non-pecuniary interests, with mandatory reporting for pharmaceutical and medical device industries of payments made to teaching hospitals, research institutions and clinicians.
9. Task force to implement Review recommendations: Patients across the NHS and private sector must have a clear, well-publicised route to raise their concerns about aspects of their experiences in the healthcare system. Review heard of “frustration at the lack of a clear pathway for them to make a complaint or raise concerns about aspects of their care”.

We would urge you to write to your MP to demand that the recommendations are implemented without delay. The APPG are writing to Matt Hancock MP the Secretary of State for Health and Social Care pointing out that the Cumberledge Report has provided the government with opportunity to address decades of unnecessary suffering and put measures in place to ensure such suffering is not repeated.

The second half of the meeting addressed the issues in the lack of face to face consultations for people with epilepsy for many months. In many areas they only ever took place once a year traditional clinic had not been running since the start of lockdown in March. Whilst action on Covid-19 is important It must not be allowed to bring treatment for other conditions to a halt. Epilepsy is a serious condition leading to many deaths which shatter the lives of loved ones left to grieve.

International Association of Patients Organisations (IAPO)

This year is the 21st anniversary for the above organisations and Epilepsy HERE has been a member organisation since the first congress at Heathrow Airport. Their purpose is to enhance the voice of patients in any part of the world through promoting the World Health Organization with whom they work closely.

They boast that everything they do is focused on promoting patient-centred healthcare. They do this by being the global voice for people who suffer from any disease, disability, illness, impairment or syndrome, and by being the focal point for patients' organizations around the world.

We have attended many of the Global Congresses held every other year

The Global Patients' Congress (GPC2020) has now been re-designed as a virtual event on 16 and 17 September 2020 with a focus on patient co-creation of innovative healthcare during and beyond COVID-19. The second day of Congress is coinciding with the World Patient

Safety Day 17th September 2020, whose theme is 'Health Worker Safety: A Priority for Patient Safety'.

Global Patients' Congress (GPC2020)

The re-designed 9th Global Patients Congress (GPC 2020) will be a moment to reflect on the defining health crisis of COVID-19 and its impact on the global patient community. The Congress will be an opportunity for focused conversation on the next steps in health system strengthening and preparedness through patient led and co-created innovative solutions in 2020 and beyond.

GPC 2020 will be a moment for the global patient community to engage in focused discussions on health systems strengthening and preparedness today and in the future through patient led and co-created innovative solutions, and mark the World Patient Safety Day 2020

If you wish to know how to register for the event go to <https://gpc2020.vfairs.com/> If the dates and times are not convenient the website will be open for some days after the end of the physical conference. All participants are welcome

Christmas cards

Sadly the task of sourcing, ordering, storing and selling cards which normally takes much of our time from now until the end of November is denied us this year since there are so many uncertainties. However, if you wish to buy cards or other Christmas goods in support of Epilepsy Action you can telephone 01132108851 or 8832 or visit www.epilepsy.org.uk/christmasshop

Epilepsy Society www.epilepsysociety.org.uk Epilepsy Research UK www.eruk.org.uk and Young Epilepsy www.youngepilepsy.org.uk also face severe challenges to their finances so keep visiting their websites for any help you can give them

Keeping the internet safe for people with photosensitivity

Epilepsy Society raised concerns with the GIF (animated image) library, whose GIFs are used on social media platforms including Instagram and Twitter. This was following the ongoing Twitter attacks where internet trolls are targeting people with epilepsy with flashing images with the deliberate intent to trigger a seizure. The charity's social media team identified that certain GIFs used in the attacks were in the library, and flashing images appeared as results to many epilepsy-related search terms.

A bespoke fast-track flashing image reporting line has been created for the charity to be able to work with them efficiently to locate malicious or harmful content. GIPHY have deleted GIFs within their library that Epilepsy Society identified are used frequently by the trolls.

Epilepsy Society will continue to work with GIPHY to introduce safeguarding measures for people with epilepsy.

The charity's social media team have also raised concerns with the GIF library Tenor about similar issues. Support our campaign by [writing to your MP](#) about the Online Harms Bill.

Ed. Note. I have edited and written much of the 21 volumes of this newsletter to bring to notice news of the events we have attended and meetings we have arranged since 1999. We have travelled many miles in the United Kingdom and sometimes in Europe to discover what is needed to improve the lives of people with epilepsy. I know from remarks made to me that the nurses have sometimes found items of interest they might otherwise have missed. Monica has also spent many hours proof reading and correcting many errors of spelling or grammar. Since I am now severely restricted in my ability and approaching my 90th birthday we now need people to take over. If you can do this or have internet skills to update the website email herebay@aol.com or telephone 07435005409 to talk it over

