



Epilepsy HERE

**Charity Number
1079172**

Tel: 01227 273747 or 01227 360207

e-mail: herebay@aol.com

website www.epilepsyhere.org.uk

Newsletter vol 21 number 3

What have we been doing since lockdown

During the first period of lockdown after having left the office without much notice we had to first persuade the broadband provider to understand we did not have physical access to the landline telephone and for them to arrange for all calls to be diverted to the line at our home. Between the two lockdowns Melinda and Colin did valuable work in sorting through old records and publications in case we had to vacate the office on which we continue to pay rent. Roger and Monica attended from time to time and discussed what action we needed to take to organize holding an Annual General Meeting on line by zoom or some similar method. There will be more news about this AGM in the next newsletter because we have to hold the meeting in the early part of next year. Our financial year 2020-2021 ends on 31st March 2021

Changes to the constitution of Epilepsy HERE

The trustees have approached the Charity Commission to approve changes to the constitution and have obtained their consent. The changes were necessary to record recent changes in the area of operation of the Kent Community Trust which now operates the Epilepsy Nursing Services throughout Kent and Medway for adults and children. At the same time it was necessary for the trustees to make administrative changes to make it easier to operate during the coronavirus pandemic. Firstly because of uncertainties about how many members we have the details were changed to allow all those who have asked to be members and have attended a meeting either face to face or online within the last two years to be members.

To allow certainty of the possibility of holding a general meeting as we are bound to do each year the quorum has been reduced to six and other changes confirm attendance at online meetings are equally valid with face to face attendance. Finally, a specification of who the members may nominate to be there proxy in any vote to be any member of the management committee. The amended constitution has now been published on the charity commission website at www.charitycommission.gov.uk. If you wish to have a copy of the amended constitution please let us know

Epilepsy Research

Although the Epilepsy Research Association were able to give a record amount to projects this year not only has the pandemic but also the end of the transition period has left their prospects for 2021 and beyond much more uncertain. In a letter to us from Maxine Smeaton the Chief Executive of the charity has introduced the campaign “A Life Interrupted” which we consider a very apt title. Please visit their website at www.eruk.org.uk to pledge your support and discover the various ways in which you can help the campaign. You may remember that last year we donated our part of the proceeds from the concert at Whitstable United Reformed Church given by Canterbury Musicmakers to Epilepsy Research UK as they are the main channel for epilepsy research in this country. Above all complete the questionnaire and do not forget to mention the impact that seizures have on the whole family – the cancelled plans- the interrupted sleep -the effect on many relationships. Some will even have to include Sudep of loved ones which sadly interrupt relationships with family and friends. ERUK also have a range of Christmas Cards which you can purchase since we have been unable to hold any card sales this year

Epilepsy Action

This year marks the 70th anniversary of the creation of Epilepsy Action the largest membership charity for epilepsy in the United Kingdom. The Chief Executive Philip Lee wrote a blog to mark the occasion including this short paragraph

Over the last 70 years, the epilepsy landscape has changed a lot. In 1950, when the British Epilepsy Association (BEA) was created – later renamed Epilepsy Action – life for someone with epilepsy looked very different. Some people might remember people with epilepsy being cared for in old asylums or epilepsy colonies in the early years of the decade. They might remember a time when a marriage could be annulled because of epilepsy. This was a time when epilepsy was very poorly understood and rarely spoken about.

So, the creation of the BEA marked an important moment in history. An organisation was finally set up to influence healthcare, policy and public understanding, and be a source of support for people with epilepsy.

The ways in which epilepsy touches our lives are numerous. Aside from the frightening and frustrating seizures themselves, it can affect our lifestyles, jobs, travel, livelihood, mental health, relationships and much more. It can feel lonely to be dealing with these challenges on your own. But with organisations like Epilepsy Action, you know someone has your back. They understand what you’re going through and they work to enact change for the better.

To mark its 70th anniversary, we look at seven ways that Epilepsy Action has been instrumental in driving change for people with epilepsy over the last seven decades

To see the article in full go to <https://www.epilepsy.org.uk/news/features/70-years-epilepsy-action-74801>

Royal College of Paediatric and Child Health

The latest Epilepsy12 report from the Royal College of Paediatrics and Child Health (RCPCH) highlights the experiences of children across England and Wales in 2018-19.

The report shows improvements in some areas of care, such as increased access to epilepsy specialist nurses (ESNs). These healthcare professionals help children and their families navigate the challenges of this complex condition. However, the Epilepsy12 report also highlights gaps where further improvements are still needed. The report shows improvements in some areas of care, such as increased access to epilepsy specialist nurses (ESNs). These healthcare professionals help children and their families navigate the challenges of this complex condition. However, the Epilepsy12 report also highlights gaps where further improvements are still needed.

This latest evidence shows that many children (70%) who should have been considered for epilepsy surgery had not been referred as expected. Brain surgery has the potential to cure a child's epilepsy where it affects a specific part of the brain.

MRI scans and EEGs (electroencephalograms) are tests that can help determine the type of epilepsy a child has, enabling more effective targeted treatments to be used. The Epilepsy12 study found that nearly half of children with epilepsy (44%) did not receive an EEG within the expected four weeks set out by NICE (the National Institute of Health and Care Excellence). An EEG records electrical activity in the brain using small sensors attached to the scalp.

. Mark Devlin, Chief Executive of Young Epilepsy, said:

"The Epilepsy12 report shows great work being done by many children's epilepsy services across the country but the report also shows that too many children are waiting too long for diagnostic tests or not even having the recommended tests. NHS Commissioners must ensure that every child with epilepsy has timely access to the investigations and treatments they should have to help families manage this serious condition."

"Children with epilepsy rely on investigations to help pinpoint a diagnosis and get the right treatment to control seizures. These seizures can significantly disrupt children's day-to-day lives at home, at school and with their friends. The sooner the right treatment can be identified by specialists, the better chance families have to manage their child's condition and enable them to achieve their full potential."

In other findings, the Epilepsy12 report showed that only 14% of health boards and trusts were able to integrate mental health support into children's epilepsy care, despite the increased mental health risks for young people with epilepsy. This comes amid concerns about increasing mental health issues as the country deals with the coronavirus pandemic.

Transition from children's epilepsy care to adult services was also an issue, with four fifths of children's epilepsy services (79%) reporting that there are no agreed pathways for children to move across to adult services. Where these pathways do exist, this often constitutes just one joint meeting for the young person with adult and paediatric services together.

You can read the full Epilepsy12 report at www.rcpch.ac.uk/epilepsy12. Read Millie's epilepsy surgery story on The Channel - <https://thechannel.org.uk/treatment/brain-surgery-millies-story>