



Epilepsy HERE

Registered as a Charity No. 1079172

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Meetings held on the first Monday each month (except January and August) at Headway House, Kent
and Canterbury Hospital at 6.30 p.m.

August/September/October 2018

PRIVACY POLICY

- All personal data held by us has been provided by the person concerned either directly with a request to send newsletters or by mutual authority at events we have attended
- No personal details are divulged except to trustees of the charity for a specific purpose
- The data is held on a computer which is password protected and is only available to Roger Kendall the Treasurer and Data Manager
- Primary written records are held at United Reformed Church, Middle Wall, Whitstable CT5 1BW in a locked cabinet the key to which is held by Roger Kendall

If you wish us to remove your records from our data base please send us an e-mail to herebay@aol.com and we will immediately comply

Annual General Meeting

The committee agreed to hold an Annual General Meeting on Monday 3rd September 2018 at Headway House, Kent and Canterbury Hospital, Ethelbert Road, Canterbury CT1 3NG at 6.30 pm. We shall have a talk by Dr Mohd. Sakel the Director of Neurorehabilitation for the East Kent Hospitals University Foundation Trust about the neurorehabilitation services in East Kent which we think members will find very interesting. We publish the Annual Report which will include details of last year's activities and income and expenses on the website www.epilepsyhere.org.uk very shortly and send proxy forms in ample time to enable you to reply. If you are unable to come do send a proxy since a good response enables us to meet our commitments under the constitution and continue to provide services.

There are two vacancies for trustees and Roger Kendall is anxious to hand over his duties as Treasurer if a replacement can be found

Epilepsy Nursing Service

We are pleased to welcome Maria Bishop to the Adult Epilepsy Nursing Service. She is currently on holiday but is familiarising herself with the clinics alongside Sean Seale. We hope that the final recruit to the service will be able to join the service soon.

Hospital Help Desks

We continue to run information points in conjunction with Dr Moran in the Outpatients Area at Kent and Canterbury Hospital on most Thursdays from 1.30 p.m. until 4.30 p.m. and on alternate Mondays when Sean Seale has a clinic from 1.00 p.m. until 4.30 p.m.

We are at William Harvey Hospital Outpatients Department (Purple Zone) Area B from 9.00 a.m. until 12 noon on alternate Thursdays and at Queen Elizabeth the Queen Mother Hospital Margate Outpatients Department from 1.30 p.m. until 4.00 p.m. We have a wide range of information on matters affecting people with epilepsy and welcome questions from them

Supply of medicines after Brexit

The European Medicines Agency has asked companies to plan for the UK's withdrawal from the European Union on 29 March 2019.

What about anti-epileptic medications?

The Epilepsy Society state "We are unaware of any current problems with anti-epileptic drugs but are continuing to monitor the situation closely and will publish any updates on our website.

Medical director at Epilepsy Society, Professor Ley Sander said: "It is very important that people with epilepsy have a consistent supply of their prescribed anti-epileptic medications so as to ensure maximum seizure control. We are very much aware that concerns around supply of drugs can cause anxiety for people with epilepsy which in turn has the potential to trigger seizures in some. We will be monitoring the situation and sharing any updates through our website."

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Cannabis Oil

In matters of clinical research we liaise with the charity Epilepsy Research UK which is the leading charity in the UK in the area of medical research into epilepsy. They have published the results of small scale trials showing that cannabis oil may have a beneficial effect for people with some children with some epilepsy syndromes including Lennox Gastaut. Also the governments review panel has recommended that it should be available for prescription on the NHS for some conditions. There is no change in the government's position in regard to the declassification of cannabis for recreational use where it is currently illegal.

Epilepsy Action's deputy chief executive Simon Wigglesworth said: "Epilepsy Action welcomes the recent recommendations from the government's review panels to reschedule some cannabis-based medicines. It represents an important step towards ensuring people with epilepsy who may benefit from cannabis-based medicines can access them safely and quickly.

"More research is needed into the safety and efficacy of cannabis-based medicines but yesterday's recommendations will help push this vital research up the agenda. It is worth remembering that this is particularly important for people with rare, severe and treatment resistant epilepsies.

"We thank the Chief Medical Officer, the ACMD and the government for their swift and thorough work but there is still more to do. We would urge the relevant authorities to set out which cannabis-based medicines will be made available for clinicians to prescribe as a matter of urgency.

"We look forward to the Home Secretary's response to these recommendations and will continue to follow developments closely."

The committee will also be providing longer-term advice to the UK government. The Home Office has said it is considering the recommendations and a decision will follow soon.

Cannabis for recreational use will remain illegal in the UK.

Protein Found In Worms Helps to Stop Seizure Activity

Exciting new research that involves using a protein in worms to suppress seizures, could spell hope in the future for thousands of people with epilepsy.

Scientists at University College London (UCL) have used a chemical found in worms to reduce seizure activity in the brains of epileptic rats. The chemical produces a protein that quietens down brain activity when glutamate levels build up causing neuronal excitement in the brain.

The chemical is delivered into the brain by injecting it through the skull inside a harmless virus. Using a technique called gene therapy; this enables the worm DNA to spread throughout the brain.

Epilepsy Society's medical director Professor Ley Sander described the new technique as very promising but cautioned that there was still a long way to go before the technique could be safely used in humans.

Epilepsy Society Conference

The next conference to be organized by the Epilepsy Society will be on Saturday 15th September 2018 at Holiday Inn, Bloomsbury. The programme will include presentations by experts on such issues as "The importance of a person centered approach to epilepsy treatment." "Advanced Imaging Techniques"" "Sleep issues and cognitive behavior therapy" and questions to an expert panel drawn from the days speakers. A good number of our members have already registered and the full programme is shown on the website at www.epilepsysociety.org.uk. The cost of the day long conference including lunch is good value at £25.

Young Epilepsy purple Walk

Roger and Monica joined their 10k sponsored walk at Chiiddingstone Castle on Sunday 24th June 2018 and found it to be a very challenging course. They raised over £450 for the charity which provides a home, school and further education centre at Lingfield in Surrey as well as being a major charity for young people with epilepsy.