



Epilepsy HERE

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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

June Meeting

After a gap of two months our meetings resume On Monday 4th June 2018 at 6.30 p.m. at Headway House, Kent and Canterbury Hospital, Ethelbert Road, Canterbury CT1 3NG when Roger will talk about the Masterclass in status epilepticus which he recently attended at Corpus Christi College, Oxford. This is a subject that should be understood by those with epilepsy or those who care for them.

The masterclass brought together some 80 clinicians and others with an interest in epilepsy and they heard talks from experts from across England. At the recent committee meeting we agreed to hold a meeting on the second Monday of the month if the first Monday is a public holiday.

Young Epilepsy

Are you a young person living with epilepsy? Fancy the chance of winning a £40 Amazon voucher?

Help Young Epilepsy understand how digital services could better support YOU. Just take a moment to complete this short survey.

<https://t.co/xQ6KSYphK>

Epilepsy Nursing Service

We are pleased to say that following the departures of Annette Clarke and Stephanie Garwood the recruitment process is well advanced and Helen Hordle is in post and in the induction process. A new nurse is expected to start in June and recruitment process continues to find one further nurse. We would like to thank Sean Seale for his efforts to maintain the service during challenging times. We know this has meant greater travel for many people with epilepsy in East Kent. But from next autumn there should be more clinics closer to home. If in the meantime you receive an appointment which you cannot attend please do let the nursing service know as soon as possible so that someone else can benefit from the time.

Coffee Mornings

We have joined with Whitstable United Reformed Church where we have our offices on the third Tuesday each month for over a year. The idea of these meetings is that those who would like to keep in touch but cannot attend our evening meetings can meet in the daytime. However since attendance has been falling over recent months we may have to reconsider whether this venture is proving worthwhile. We shall continue to be available on the third Tuesday of June and July and hope more members are able to come.

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 will send the Annual Report which will include details of last year's activities and income and expenses and proxy forms in ample time to enable you to reply.

A good response enables us to meet our commitments under the constitution and continue to provide services.

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Visit our website www.epilepsyhere.org.uk

Epilepsy Research UK reception

We were grateful to be invited to a reception at the Royal Society in Carlton House Terrace just behind the Mall in London. ERUK invited us because we have been selling their Christmas Cards for almost twenty years and we were warmly welcomed by Prof. Matthew Walker their Chairman of Trustees and Shona Scott who has sent their cards to us for many years.

Prof. Walker thanked all those present and introduced spokesmen or researchers for the recipients of new grants this year.

Mr. Ashan Jayasekera from Newcastle University will investigate whether high levels of glutamate an excitatory chemical in brain tumours can pick out areas that generate seizures. *The study has been funded by £173,924 over 2 years*

Dr Vincenzo Marra from the University of Leicester will study the structures within cells which generate seizures. Recently it was discovered that epileptic brains reorganise these structures perhaps in an attempt to stop nerve cells firing at the same time. Establishing the role of these synaptic structures will advance our understanding of the cellular and molecular bases of epilepsy. *This research receives a grant of £56,852 over 36 months*

Prof. Mark Richardson from Kings College London will research the triggers which some people with epilepsy experience such as tiredness, fatigue or missed medication. He will investigate whether EEG signals which can predict when seizures may happen could be monitored by patients with epilepsy being trained to record their EEG in a few minutes. A group of patients with epilepsy will be trained to take their own EEG and will also be asked to wear a wristwatch device that records movement and heart rate at home for 10 minutes every day. The researchers hope this will enable the development of a wearable device to predict seizures. *This project has been granted £148,372 over 24 months.*

Dr. Vasiliki Tsirka of Royal London Hospital will discuss the role of continuous EEG monitoring which is often employed in unresolved cases of status epilepticus in Intensive treatment units and whether its use improves the final outcome such as survival or side effects. *£149,290 over 2 years*

Dr. Tonni Veenith from the Queen Elizabeth Hospital, Birmingham will study whether treatment of status epilepticus in high volume centres enable clinicians with greater experience in managing the condition have better patient outcomes than those in centres with fewer patients with status epilepticus Awarded £5,000 pilot grant over 12 months

Dr. Simon Keller of University of Liverpool will investigate Anti-epileptic drugs which control seizures in 60% of patients with epilepsy It is not known why they do not do so in the other 40%. If we knew why this was and could predict from the point of diagnosis which patients would not have their seizures controlled it would be possible to consider alternative treatment at an earlier stage. *This exciting project has been granted £373,220 over 18 months.*

Prof. Kirill Volynski of University College London will investigate the connection between epilepsy and migraine. and why the excessive firing of neurons known as hyperexcitability rapidly invades other brain areas in epilepsy but not in migraine. This will enable researchers to investigate why some brains are susceptible to seizures whilst others are prone to auras in migraine. *This has been awarded £149,931 over 36 months*

Dr Jessica Kwok of the University of Leeds will study the effect of extracellular structures called perineural nets which are responsible for synaptic stabilisation and are involved in the control of cell excitation, growth and cognition Awarded £149,633 over 24 months

Dr. David Carmichael of Kings College London will conduct a pilot study of transcranial electrical brain stimulation which is safe and does not hurt. in Juvenile Myoclonic Epilepsy Awarded £29,960 over 11 months

Prof Peter Oliver of Oxford University will investigate the role of gene TBC1D24 a gene known to cause epilepsy in particular families Awarded £30,000 over 24 months

Prof. Deb Pal of Kings College London will conduct a study of the use of nicotine patches for people with sleep related hypermotor epilepsy who rarely obtain relief from conventional means. Awarded £30,000 for pilot study over 24 months

Prof Maria Thorn and colleagues over a two year period will restore the Corsellis epilepsy tissue collection. Prof Corsellis was an eminent neuropathologist who published important studies. The collection comprises tissue samples from people who died from epilepsy between 1950 and 1997 and has been given to University College London. Epilepsy samples are becoming rare due to medical advances and changing attitudes. Awarded £47,000 over 24 months

We were extremely pleased to hear of the extensive research being undertaken and to know that our small contributions are put to good use.

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Sodium valproate

Although sodium valproate is an effective drug in controlling epileptic seizures and for some people may be the only medication that works it should not be recommended as a first line of treatment for women of child-bearing age because of potential risks to the foetus during pregnancy in women of a childbearing age,

A recent European review called for more to be done to ensure all girls and women of child bearing age who are prescribed sodium valproate are fully informed of the risks and are only prescribed the medication if no other treatment is able to control their seizures and if the patient is fully informed of the need to use effective contraception to avoid a possible pregnancy.

- This means that if your doctor decides in collaboration with you that sodium valproate is the only medication that will effectively control your seizures they must also discuss the need to use effective contraception to prevent you becoming pregnant. This is to safeguard against a future baby being born with an avoidable disability.

- Depending on the type of contraception that you and your doctor consider to be best. Regular pregnancy tests might be needed to ensure you do not become pregnant

- Your epilepsy specialist must also invite you for a review of your epilepsy medication at least once a year to review your treatment and discuss the risks around the medication.

- You may be asked to sign a risk acknowledgment form and should also sign it to show that you have discussed and understand the risks and also the need for effective contraception.

- When you receive the medication your pharmacist should show you the warning on the packet. Make sure you see the patient information leaflet and ensure you have had a review by your doctor within the last twelve months

- **If you are a female child or woman of child bearing age who is already taking sodium valproate do not stop taking the medication but make an appointment to see your doctor immediately .You will then be able to discuss the best action to take**

Epilepsy Society Conference

The conference will be held at Holiday Inn, Bloomsbury on Saturday 15th September 2018 from 9.30 a.m. to 5 p.m.

The hotel is within easy reach of St Pancras International Station. The cost is £25 including lunch and those who attend be able to hear from some of the world's leading experts in epilepsy including Prof. Ley Sander their medical director and the clinical lead at their assessment and treatment centre Dr Fergus Rugg-Gunn. They will be joined by members of their research team.

.To book go to

epilepsysociety.org.uk/annual-conference

Young Epilepsy

The charity which runs a school, further education college and assessment and treatment centre at Lingfield in Surrey will be holding a Purple Walk for Epilepsy on Sunday 24th June 2018 at Chiddingstone Castle near Edenbridge

Soak up the historic atmosphere on our 10k circular walk starting at Chiddingstone Castle in Kent. Enjoy afternoon tea in the castle tearooms or stop for a refreshing drink at Hever's Henry VIII Inn. There will be a shorter walk option and for those wanting to truly enter the spirit, some fun Tudor-style games. Registration includes a free t-shirt and medal. Under 5s go free!. Roger and Monica hope to attend and walk as far as the terrain allows. Please sponsor them for every kilometer they walk.

Epilepsy Helpdesks

We continue to hold information points at hospitals which are staffed by people knowledgeable about epilepsy through personal experience. You are likely to find us in the outpatient's areas when a clinic is held for patients with epilepsy

We are usually at Kent and Canterbury Hospital on each Thursday and alternate Mondays in the afternoon. In addition we maintain leaflet stands there and at Queen Elizabeth the Queen Mother Hospital in Margate where we have an information point on alternate Thursday afternoon

We are in Purple Zone Outpatients area B on alternate Thursdays from 9.00 a.m. to 12 noon