



Epilepsy HERE

Registered as a Charity No. 1079172

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February Meeting

After a brief introduction about the modern duties of his role as Sheriff of Canterbury Cllr. Colin Spooner gave an interesting talk about his former role as Police Officer and Police Dog handler. He recalled how the training for this took place with the chosen dog living with the handler and his family. Although this has changed in the present day to include such uses as a means of finding illicit substances and explosives in earlier days it was mainly concerned in finding and apprehending offenders and pinning them down until they could be questioned and arrested. Clearly the dogs he had handled had meant a great deal to him and the last dog he handled retired with him. After leaving the Metropolitan police force he ran kennels in Whitstable. At the end of his talk we held a discussion with him about the many roles in which dogs assist those with disabilities and health issues including Seizure Dogs of which he was already aware.

Christmas Card Sales

In total last year from our sales in East Kent we were able to forward sums of £820 divided between those three charities whose research into epilepsy is so vital if they are to find cures and treatments. We have received letters of thanks from Epilepsy Society who have a large dedicated research building where they conduct genetic research, Epilepsy Research UK who fund a variety of academic research into many aspects of the condition and Young Epilepsy who are concerned with research into paediatric cases of epilepsy as well as having a school and further education college for young people with epilepsy.

Coffee Morning

We resume our monthly coffee mornings from 10.00 a.m. to 11.30 a.m. at Whitstable United Reformed Church, Middle Wall Whitstable on Tuesday 20th February 2018. All welcome

Chairman appointed to lead Trust

A new permanent chairman for East Kent Hospitals has been appointed to lead the Trust. Professor Stephen Smith is currently a Non-Executive Director for Great Ormond Street Hospital. He is a gynaecologist by training and has held prominent positions including as Professor of Obstetrics and Gynaecology at the University of Cambridge before becoming Principal (Dean) of the Faculty of Medicine at Imperial College, London.

He has published more than 230 papers on reproductive medicine and cancer. He was awarded his Doctor of Science in 2001 for his work in Cambridge on the complex gene pathways that regulate the growth of blood vessels in reproductive tissue. He led the formation of the UK's first Academic Health Science Centre at Imperial College Healthcare NHS Trust and was the Trust's CEO from 2007-2011. Stephen was founding Dean of a new joint medical school between Imperial College and Nanyang Technological University Singapore, the latter one of the top four universities in Asia.

He will therefore be well prepared to lead the trust in their efforts to promote a new medical school in Kent being widely experienced in health services at home and abroad.

Most recently Stephen was Dean of the University of Melbourne for two years until September 2015 where he was also a Non-Executive Director. He was a Non-Executive Director at the National Healthcare Group, one of the three comprehensive medical groups in Singapore of the Royal Melbourne Hospital and the State of Victoria, Comprehensive Cancer Centre in Australia.

Epilepsy Nursing Service

At present the Epilepsy Nursing Service in Kent is under pressure. They are recruiting to fill vacancies and expect to interview candidates shortly. Training and notice period for anyone appointed is likely to take some time. During this period you may be asked to attend at a different location and appointments are likely to be less frequent. It is of the utmost importance that if you are unable to attend clinic at a time or place you are offered that you inform the service as soon as possible so that others may be given the opportunity of an appointment

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Switching Epilepsy Medication

The government has added to its guidelines about switching between different forms of epilepsy medicines. The update says that prescribers need to take into consideration people's thoughts and concerns. Switching can sometimes happen between different manufacturers' versions of a medicine. This includes generic versions and brand-name versions.

For example, someone taking Lamictal may be put on a generic form of lamotrigine. A change from a particular manufacturer's product can sometimes cause an increase in seizures or side-effects.

The update states that people's feelings should be considered when deciding whether to switch between versions of medicines. This includes whether people have negative thoughts about different forms of a medicine, like packaging and taste. Prescribers should also consider problems such as anxiety, confusion, dosing mistakes and people not keeping up with their medicine.

Can we keep in touch with you?

We are happy to send you newsletters and updating information from time to time. We may also wish to send you a text if anything urgent arises so that we need to make sure you need to know in time.

Government rules are changing in May to limit people receiving mail or telephone calls they do not want, so that we must ask you to confirm you are happy about this.

All you need to do for us to continue to contact you is to send us an e-mail in reply to this saying "yes send" or if you do not wish to hear from us send one saying "stop sending". Also if you change your e-mail address at any time please let us know.

You may change these instructions at any time by sending us an e-mail.

Purple Day

26th March every year is the International day for epilepsy organisations to raise awareness about epilepsy. On this day which was originally suggested by Cassidy Megan then a young girl in Nova Scotia Canada groups in many countries including the UK hold fundraising and other events and wear something purple to show their involvement. See epilepsysociety.org.uk and epilepsy.org.uk for examples of what to wear.

EMA medicine safety committee recommends stronger restrictions on use of sodium valproate in women of childbearing age

The new recommendations say that for women with epilepsy, sodium valproate should not be used during pregnancy. However, the recommendations acknowledge that in some women with epilepsy, it may not be possible to stop using the medicine. This is because it may lead to breakthrough or worsened seizures, which can be harmful to the woman and baby. In this situation, the recommendations say women should have appropriate specialist care.

In women of a childbearing age, the recommendations say that sodium valproate should not be used unless measures are taken to help the woman avoid becoming pregnant. The PRAC suggests that a pregnancy prevention programme should be created for this.

The pregnancy prevention programme would assess the potential of a woman becoming pregnant, depending on her circumstances. It would suggest pregnancy tests are taken during the treatment as needed. The committee says counselling should be provided about the risks to pregnancy as part of the programme. It also suggests that there should be annual reviews of the treatment. PRAC recommends that a risk acknowledgement form should be introduced, for people to go through with their doctors at each review.

Alongside these recommendations, the committee has also said that there should be a visual warning on the medicines' packaging. They recommend a symbol or a pictogram. A reminder card should also be attached to the packaging to help pharmacists discuss the risks of valproate. The committee is also calling on companies marketing the medicine to provide updated educational materials.

March meeting

The next meeting will be on Monday 5th March 2018 at Headway House, Kent and Canterbury Hospital Ethelbert Road CT1 3NG. There is a bus service to the hospital from Canterbury Bus Station. The meetings start at 6.30 p.m. and end at 8.00 pm. to allow for people to catch the bus.