



Epilepsy HERE

Registered as a Charity No. 1079172

Whitstable United Reformed Church, Middle Wall, Whitstable CT5 1BW

Telephone: 01227 274757 e-mail: herebay@aol.com

and at 11, Beaumanor, Herne Bay, Kent Telephone: 01227 360207

Mobile (44) 07435005409

Meetings held Monday monthly (except January & August) at Headway House, Kent and Canterbury Hospital, Ethelbert Road, Canterbury CT1 3NG at 6.30 p.m.

"Coffee Break" at Whitstable United Reformed Church every third Tuesday each month 10.00 a.m. to 11.30 a.m.

Volume 19 Number 5 November 2018/December 2018

November Meeting

The meeting on Monday 5th November 2018 is at Headway House, Kent and Canterbury Hospital at 6.30 pm. The venue is alongside the far wall of the hospital past the Outpatient entrance.

Sean Seale the Epilepsy Nurse Specialist who will give us his views on the International League against Epilepsy (ILAE) British chapter scientific meeting held in Birmingham during September

Christmas Card Sales

We shall once again be selling Christmas Cards in aid of charities which support and carry out research into epilepsy at various venues in East Kent in the coming weeks of 2018

On 27th October we shall be at St Nicholas at Wade Church in Thanet at their Charity Day from 10 a.m. to 3 p.m.

On 3rd November we shall be at Frinsted Village Hall near Sittingbourne for their monthly charity sale from 10.30 a.m. to 12.30 p.m. and also at Whitstable United Reformed Church, Middle Wall, Whitstable from 9.30 a.m. to 1 p.m.

On 24th November we go to the Minster Surgery Patients Liaison Group Fair at Minster Old Schools (next to St Mary's Church) in Minster in Thanet from 9 a.m. to 1 p.m. then

On 1st December 2018 we will be at the Action for Children Fair at St Peter's Methodist Church, Canterbury from 10 a.m. to 3 p.m.

The cards will also be on sale at our help desks at Kent and Canterbury Hospital on most Thursdays and some Mondays until early December

Over the years these sales have raised several thousand pounds for Epilepsy Society, Epilepsy Research UK and Young Epilepsy the charity supporting young people with epilepsy at Lingfield in Surrey

Annual General Meeting

A well-attended meeting attended by the Sheriff of Canterbury and her husband Cllr. Ian Stockley on behalf of the City Council heard from Dr. Mo Sakel the Director of Neurorehabilitation about his work for the East Kent Hospitals University Foundation Trust. In particular he spoke about research being undertaken in support of all those with neurological conditions.

After this the current team of Trustees were re-elected together with Matthew Geliot as a new trustee

The new committee will therefore be

Monica Kendall – Chairperson

Colin Barnes – Secretary

Roger Kendall – Treasurer

Melinda Barker

Patricia Dickson

Matthew Geliot

December Meeting

The meeting on Monday 3rd December 2018 will be the anniversary meeting at the start of the twentieth year of our organisation which became a registered charity in January 2000. We have provided helpdesks at Kent and Canterbury Hospital continually since 1998 and now have additional points at William Harvey Hospital, Ashford and Queen Elizabeth the Queen Mother Hospital, Margate.

We feel that it would be good to celebrate this since during these years we have provided information to several hundred of people with an interest in epilepsy.

We shall have our usual refreshments of mince pies and sing Christmas Carols.



SEASON'S GREETINGS TO ALL OUR READERS



Financially supported by
Ronald Cruickshanks Foundation



Follow us on twitter
@epilepsy here

Epilepsy HERE

Volume19 Number 5
November/December 2018

The Epilepsy Society Conference

The conference held in London on 15th September, 2018 was attended by seven of our members and after registration Clare Pelham the Chief Executive introduced herself and gave us some background information on her own achievements in the past. She told us about Peter Worthington the Chairman of the Board of Trustees since the death of the last Chairman and how they will work together for the good of the Society. Following this welcome Mr. Worthington he similarly told the audience about his background and intentions working towards the good of the Society and the wellness of the patients with epilepsy but looking forward to the new challenges.

Professor Ley Sander continued with his theme being that of the progress made in the field of epilepsy and it was said to be great largely because of the improvement of the scanners showing so much more now than ever before and the understanding of the working of all the other parts of the brain telling how intricate the different parts of the brain together with the parts around the place where the trouble in the brain, how the uncertainty in the past the not knowing the way in which all the parts of the brain were located and the types of damage that could occur.. Learning when the first seizure occurred was it following an injury to the brain, or a very high temperature. Needing another person to describe the way a seizure happened the duration and what happened during the event or recording it with a camcorder. A break for lunch was taken which as well as lunch was an opportunity to catch up with contacts made a while back and make new acquaintances too after which **Dr Hugh Selsick** gave a talk on sleep and cognitive behavioural therapies. Many of the tablets have side effects many of which lead to the way in which patients respond to others and the ability to sleep and items surrounding this.

Dr Fergus Rugg-Gunn then talked about the importance of the newer scanners and what consultants are able to gain from these more sophisticated scanners and the additional information they get from these, How issues on the brain are highlighted and make it easier for the epilepsy to be located and tackling such operations and how to go straight for the parts of the brain that need interventions knowing what these parts of the brain control, blood vessels be they vascular, veins or arteries or to carry blood away or deliver blood to areas of the brain.

Rev. Bob Mayo a London vicar who has epilepsy spoke about his need to keep various diaries to enable him to keep up with daily life and his ministry as an Anglican priest. As the vicar of a large London parish he finds epilepsy is a slog especially if he has a seizure midway through a service
The meeting closed with a question and answer session with an expert panel of speakers.

Epanutin (phenytoin) 30 m/5ml Oral suspension Supply disruption

The Department of Health & Social Care have informed all Heath trusts and NHS Regional Offices that Pfizer who are the sole license supplier of this product will be out of stock from 29th October until early December 2018. If you have been prescribed this medication you should check whether you have sufficient stock already to last until mid-December. If this is not the case you should immediately inform your GP or other prescriber. The prescriber will have been given guidance as to what action to take. You will be unable to receive a repeat prescription during this time.

Epilepsy medicines pregabalin and gabapentin to be reclassified as class C drugs to help minimise possible misuse

The UK government announced last week that the medicines pregabalin and gabapentin will be reclassified as class C under the Misuse of Drugs Act 1971. The change will take place in April 2019. Patients prescribed this medication should make sure that unused tablets are kept securely to avoid misuse.

The Neurological Alliance launches third patient experience survey

The Neurological Alliance is carrying out its third patient experience survey. The alliance is asking people with neurological conditions, such as epilepsy, to share their experiences of neurology services. The survey is available online <http://www.myonlinesurvey.co.uk/NA18EA/CT/> and it is a matter for you to decide if you wish to take part.

Future Meetings

There is no meeting at Headway House in January 2019 so the first meeting next year will be Monday 4th February 2019 from 6.30 p.m. to 8.00 .p.m. You are welcome to join us for coffee at Whitstable United Reformed Church, Middle Wall, Whitstable CT5 1BW on the third Tuesday of each month from 10.00 a.m. to 11.30 a.m