



Epilepsy HERE

Registered as a Charity No. 1079172

The 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 first 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 from 10.00 a.m. to 11.30 a.m.



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February Meeting

We wish all our readers a very happy New Year. We plan to use this meeting to discuss how we can improve the impact of our charity as it enters its 21st year. We need to find speakers who are of interest to a greater number of members to attend and plan ahead for at least a few months so that we can inform members earlier of what is taking place

We wish all our readers a very happy New Year. If you are unable to attend but have ideas to improve the programme please let us know,

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If you shop online at Amazon you can let Amazon pay 0.05% of the purchase price to charities. Just go to smile.amazon.co.uk and enter our name as the charity you wish to support and the donation will be credited direct to our account.

Epilepsy Society Brain and tissue Bank

Research into human brain tissue has already shown significant results. For example, it has helped to underline the importance of wearing helmets for those with repeated seizures which might cause falls and head injury. Research has established that it is the number of times a person hits their heads rather than the number of seizures that can cause some types of cumulative damage to the brain. Brain and tissue-based research can also investigate mechanisms that may increase the risk of sudden and unexpected death in epilepsy.

Research has also contributed to findings that show how a correct diagnosis of Dravet syndrome – a difficult-to-treat form of epilepsy that can occur in early infancy – could still lead to improved quality of life and cognitive performance. They need brain and other tissue donated by people with and without epilepsy so researchers are able to compare differences. To become a donor, you need to join our donor register by calling our Brain and Tissue Bank team on 020 3448 4009 or emailing us at epilepsybrainbank@ucl.ac.uk.

The team will send you further information and the forms **for you to complete**.

South East Water Priority Register

South East Water offers extra assistance through our **Priority Services Register**, which is free to join.

They offer a range of special services – not only for those with mobility restrictions, but also for our customers who have additional needs such as a hearing or sight impairment, disabled or suffering from a long- or short-term illness.

Special services include:

- Receiving prior warning of planned work which may interrupt your water supply.
- Receive priority treatment should your water supply be interrupted (we aim to arrange an alternative source as quickly as possible, and will often hand-deliver bottled drinking water to our customers with mobility issues).
- Receive important information in a more convenient format, such as easy-to-read large print or the spoken word, where our normal presentation style is not suitable.
- Register your own spoken or written password for our staff to use so that customers can identify them if we need to call at your home.
- Receive information about specialist organizations which are able to provide advice on possible adaptations to water fittings and appliances around the home.
- If English isn't your first language, we may be able to help you with our interpretation service when you call.

To register for priority services, please visit : www.southeastwater.co.uk/get-help/help-for-priority-customers

March meeting

The next meeting at Headway House is on Monday 2nd March 2020 at 6.30 p.m

St Valentine's Day

It's a little-known fact that while St. Valentine on February 14th is widely associated with love and the giving of 'valentines', he is the patron saint of people with epilepsy. He is also the Patron of Beekeepers.

Financially supported by





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How A Tweet Went Viral Raising Thousands for Epilepsy Research

On Friday, a young woman, Hari Miller, tweeted a post about an order of service she had discovered in her desk drawer Hari had started a new job, and it was only once she had been given the keys to her desk that she found the service order for 21-year-old Amelia Roberts, who had died of Sudden Unexpected Death in Epilepsy.

The beautiful picture of Amelia and the moving words of her parents Hamish and Debbie Roberts, touched Hari and she decided to share it on Twitter, knowing that her friends would be moved by Amelia's story. She also messaged Amelia's family to make a donation to her JustGiving page. Twenty-four hours later, Hari's post had gone viral, with likes, retweets and donations flooding in from around the world.

By Monday morning, Amelia's fund had climbed from £80,000 to more than £114,000. With offline donations, the fund now sits at over £140,000.

April Meeting

Anna Gould from Kent Fire and Rescue Service will talk for about 45 minutes and will focus on safety in the home currently includes:

- Engaging with people to understand their lifestyle and motivations highlighting any risks from fire in the home
- Advising them on how to reduce those risks and encouraging safer behaviors

Fitting smoke alarms where necessary

Providing specialist equipment where necessary (e.g. fire proof blankets, deaf alarms etc.)

- Screening and making referrals to other agencies for support
Telecare assessments
Offering advice about keeping warm in the Winter

We hope for a good attendance for this meeting as Anna is giving up her time for this presentation. As always all are welcome and refreshments are provided

Dates for your diary

We shall have a stall at the United Reformed Church, Middle Wall, Whitstable on 28th March 2020 from 9.30 a.m. until 12.30 p.m. The church will be having a Craft /Bric- a - Brac stall, a raffle and will serve refreshments. We shall have a competition for a very large teddy bear kindly donated by Laurence Ward. This is currently sitting in our office.

Canterbury Music Makers

Those of you who enjoyed the Concert of English music given by Canterbury Music Makers in March last year will be pleased to hear they have kindly agreed to give another concert on Saturday 18th July 2020 with as last year 50% of the proceeds to the church and 50% to us which we shall donate to Epilepsy Research UK. They provided grants of millions of pounds to researchers for universities and hospitals.

Purple Day for Epilepsy is 26th March

Cassidy Megan a young girl from Nova Scotia in Canada thought of Purple Day for Epilepsy in 2008 and made it happen in many countries throughout the world

She has epilepsy and wanted to get people talking about the condition. Cassidy decided to use the colour purple because lavender is recognised as the international flower of epilepsy. Cassidy not only wanted to raise awareness but also. assure people with epilepsy that they are not alone

The epilepsy nurses will again hold a Coffee Morning on Thursday 26th March 2020 at Whitstable and Tankerton Hospital main entrance to raise funds for Epilepsy Action. Why not go along at 10.00 a.m. to 12 noon to support them in this endeavour. All the money raised will go to Epilepsy Action the largest epilepsy membership organisation in the United Kingdom

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