



Epilepsy HERE

Registered as a Charity No. 1079172

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Meetings held 1st Tuesday monthly (except January & August) at Canterbury Umbrella Centre, St. Peter's Place, Canterbury at 7.30 p.m.

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

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Annual General meeting

The Lord Mayor of Canterbury Cllr. George Metcalfe and the Lady Mayoress Mrs. Lillian Metcalfe will attend the AGM. This will be held at 7.30 p.m. on Tuesday 5th July 2016 at Canterbury Umbrella Centre, St Peter's Place, Canterbury CT1 2DB. We are in the process of confirming speakers and will e-mail their names and put them on the website as soon as they are confirmed.

All Party Parliamentary Group

The next meeting of the APPG will be on 13th June 2016. The subject will be **Epilepsy in the Workplace: Breaking down the barriers** The main speakers will tell those present about the problems of people with epilepsy in obtaining employment and how their organisations are helping overcome the problems.

If you have any particular points you wish us to raise whether positive or negative please tell us by e-mail or telephone since we usually have an opportunity to raise such issues at the end of the meeting.

Help wanted- lunch provided

A group of researchers at University of Kent are trying to develop mobile phone technologies which can help people with epilepsy. They are looking for people with epilepsy to take part in a half day workshop to study the usability of technologies for epilepsy management. The workshop will take place from 10am-3pm including a free lunch on 21 June at University of Kent. They will compensate for your time spent in this study. If you are interested, or if you have any question, please contact Lu Bai L.Bai@kent.ac.uk or tell us

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Government must prioritise people with epilepsy

Epilepsy Society's new chief executive David Marshall has welcomed a report calling on the government to address inadequate levels of care for people with neurological conditions, including epilepsy. The report by the Public Accounts Committee urges the Department of Health and NHS England to make neurology a priority and ensure that all its recommendations are implemented as soon as possible. The report states that over 40 per cent of people with a neurological condition do not think that local services work well together and only 12 per cent have a written care plan to help coordinate their care.

Shortcomings in neurology services include:

- the length of time taken to diagnose neurological conditions
- the wide variation across the country in services and outcomes for people with neurological conditions
- failure of NHS England to offer everyone with a neurological condition a personalised care plan by 2015.

The report details the disparity in epilepsy services across the country. The proportion of adults receiving treatment for epilepsy who remained seizure-free for 12 months ranged from 87 per cent in South-West Lincolnshire to 47 per cent in Hull and North Manchester in 2013-14. It also outlined the financial implications of poor neurology services stressing that it costs £70 million to deal with emergency admissions of epilepsy patients and many of these admissions are likely to result from shortcomings in care.

The millions of people living with neurological conditions must not be treated as an afterthought. NHS England must listen to the voices of patients and think again

Speaking as the report was published, David Marshall commented: 'This report highlights a number of concerning trends, not least the significant variation in services and outcomes across England including epilepsy death rates.'

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Pregabalin in Pregnancy

You may have read or heard of an article in the Daily Mail about a small study of 116 women 5 of whom had epilepsy which suggested an increase in the likelihood of serious malformations in babies of mothers taking pregabalin during pregnancy.

Commenting on the study, Ley Sander, medical director at Epilepsy Society and professor of neurology at University College London, said: "This is a very small study involving only five women with epilepsy so we cannot draw any firm conclusions. However it does suggest that further investigation is necessary."

"It is important that women with epilepsy discuss their medication with their GP, ideally before trying for a baby or when they are pregnant. If a woman with epilepsy is planning to start a family, this is a good opportunity for her to seek the advice of her neurologist so that issues around seizure control and risks to a developing baby can be fully discussed."

"Women with epilepsy should not stop taking their anti-seizure medication without seeking the advice of their neurologist or GP."

Midazolam Drug alert issued: 25th May 2016

The Medicines and Healthcare products Regulatory Agency (MHRA) has issued a class 2 patient level recall to be actioned within 48 hours, for a batch of **Epistatus 10mg/ml oromucosal solution pack size 1 x 5ml (Special Products Limited) Unlicensed Special (as Midazolam Maleate) Batch number: 73234 Expiry Date: October 2017** Special Products Limited is recalling the above batch because in approximately 47% of units, the neck adaptor, which reduces the size of the opening to accommodate the oral syringes, is the wrong size and is not compatible with the syringes.

June Meeting

The next meeting at Canterbury Umbrella on Tuesday 7th June will hear from the Community Outreach Officer of Thanet Citizens Advice Bureau Matthew Munson about a project being run in Thanet to provide support for people over the age of 50. The meeting will begin at 7.30 p.m and there will be the usual opportunities to talk with others and enjoy a cup of tea or coffee and biscuits

Recent benefit changes

Since our last benefits bulletin in March there have been a number of changes to the benefits system.

These include:

Scrapping the family premium in new housing benefit claims made after 1 May. The family premium is an extra housing benefit allowance paid where a claimant has dependent children. However it is no longer included in new claims. As a result housing benefit will be less generous for many families who first claim after 1 May.

Backdating of housing benefit. Housing benefit claims made since April can only now be backdated for a maximum of four weeks rather than six months.

Longer wait for help with mortgage interest. Home owners making a claim for certain means-tested benefits after 1 April have to wait 39 weeks rather than only 13 weeks before getting any help with their mortgage interest.

Cut in tax credits 'income rise disregard'. If your annual income increases, the Tax Credits Office will now only ignore the first £2,500 of any increase in income, rather than the first £5,000. This applies from April 2016.

Recovery of tax credits over payments. From April 2016, the maximum amount that can be recovered from your tax credits for an over payment in a previous year increased from 25% to 50% of your payments. However, this only applies to families with an income of more than £20,000

Epilepsy Society Regional Volunteers Co-ordinator

Sandra Attolini-Nicotera has been appointed to look after the service in the South of England and will be joining the society in a couple of weeks. We hope she will visit us at the help-desks in the months to come

"Coffee Break"

Next Coffee Break 21st June 2016 at Whitstable United Reformed Church, Whitstable CT5 1BW at 10.00 a.m. Why not come for a coffee and a chat.

Newsletter

If you have received this newsletter by post and require regular copies 4 times a year we would ask you to send a fee of £5 to enable us to meet the cost. If you have access to the internet we can e-mail a copy to you but are grateful if you are able to send the donation as it helps us maintain our services which are provided entirely by volunteers. Please also let us know if you no longer wish to receive it and wish your details to be removed from our records. The latest editions are always available on our website at www.epilepsyhere.org.uk/index.php/current-news