



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.

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May Meeting

We were pleased to welcome Lesley Riding from Healthwatch to talk about the work that they do and especially about the signposting work for all matters in the health and social care sector. She explained that Healthwatch was an independent organisation financed by Kent County Council. It was set up to replace the Local Involvement Network (Link) by the Health and Social Care Act.

If you have any question about how to access a Service and either live or work in Kent they will be able to assist you to find an answer to your problem. They also conduct their own investigations and compile reports to KCC and others about whether or not they consider services are adequate and operating to an acceptable standard.

If you wish to give your views about health or social care services in Kent you can contact them in a number of ways

By telephone on Freephone 0808 801 01 02

By e-mail; on Info@healthwatchkent.co.uk

Online at www.healthwatchkent.co.uk

By post to Freepost RTLK-Healthwatch Kent, Seabrooke House, Church Road, Ashford TN23 1RD

By text message to 07525 861 639

Annual General Meeting

The AGM will be held on Tuesday 4th July 2017 at 7.30 p.m. at Canterbury Umbrella Centre, St. Peter's Place, Canterbury CT1 2DB. We have invited Dr Sarah Phillips the Medical Director of Kent Community NHS Foundation Trust to speak or nominate a speaker for us. We are pleased that the Lord Mayor Cllr. Rosemary Doyle and Jenny Yonge the Lady Mayoress have accepted our invitation to attend.

After the speeches we shall elect a new committee to guide the charity over the year 2017-2018. So far as we are aware the present members are willing to serve but if this is not so could they please let us know.

Government changes to PIP laws against tribunal rulings could disadvantage people with conditions like epilepsy

The government made changes to personal independence payments (PIP) in February in order to restrict the number of people who qualify for this benefit. This move will mean £3.7 billion is cut from the benefits bill but will we believe further disadvantage people with neurological or mental conditions.

PIP is a government benefit designed to help people with some of the extra costs that a long-term condition or disability can cause. Last year, two tribunals were held to challenge how strict PIP criteria are. Both ruled in favour of changes that allow more people who need this support to be able to access it more by 2022, the government has rewritten its legislation to stop these changes from happening. Reports have suggested that people with epilepsy may be hit hard by the PIP changes, alongside people with learning disabilities, diabetes, anxiety and dementia.

When claiming PIP, the amount of money a person receives depends on the way their condition affects them. PIP is awarded on a points system and is based on two aspects: 'daily living' and 'mobility'. A person can be eligible for PIP based on one or both of these aspects.

The two tribunals from last year looked at how strict the PIP regulations were. One tribunal ruled that more points should be awarded under 'mobility' for people where travelling poses 'overwhelming psychological distress'. The other said that people who need help to take medication and monitor a health condition should be given more points under 'daily living'. The calling of a general election has provided the opportunity to question candidates on whether the present system militates unfairly against those with neurological conditions such as epilepsy.

We agree with the statement made by Epilepsy Action that many people with epilepsy, who need this extra support, have already missed out on this benefit because of its strict assessment process. This is before the government changed the law to make the assessment measures even stricter. Epilepsy Action criticised the PIP assessment, calling it "ineffective and inadequate", and saying that it "does not accurately assess or reflect what it is like to live with the condition." We wonder if a face to face interview on a date selected by the DWP is appropriate to assess the needs of someone with a condition whose needs vary from day to day for financial benefit and which causes confusion and exhaustion especially as there is no requirement for the assessor to have experience in dealing with such neurological or mental health issues.

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Epilepsy Society Conference

The 2017 Conference of The Epilepsy Society which focussed mainly on genetics and the human genome in particular was held at Holiday Inn, Bloomsbury on 17th March. 6 members and friends of our group attended and heard about the progress made in determining not only the genetic background to the causes of epilepsy but also ways in which an understanding of genetics could lead into improvements in treatment for the condition. There are a number of medications which although helpful in limiting the number or severity of seizures but which have serious side effects. With a greater understanding of the human genome it is hoped that these can be pre-determined and thus avoided in people likely to be disadvantaged by taking them. In the afternoon we heard from BBC playwright Louise Monaghan who has written a play to be broadcast on Radio 4 at 2.15 pm. on 1st June with epilepsy as its main theme.

EU review into Sodium Valproate in Women

The European Union regulatory body the EMA has decided to review the use of valproate based medication in treatment for epilepsy among women who are pregnant or of child-bearing age.

Sodium Valproate is an older anti epileptic medication which has proved very effective in limiting seizures in some people but which for several years has been linked to the risk of birth defects in babies born to women taking the medication during pregnancy. NICE has already strengthened its guidelines on prescribing this medication in line with EMA warnings in 2014.

In April the health authorities in France reported that they estimated that between 2,150 and 4,100 children in France had been affected by birth defects following the use of sodium valproate since it was first licensed and sold. Many of the families of those affected in this way claim that they were not adequately warned about the risks.

Pfizer and Flynn Pharma launch appeals against fine

Epilepsy Action have reported that Pharmaceuticals company Pfizer, and distributor Flynn Pharma, launched separate appeals on 7 February against the fines given by the Competition and Markets Authority (CMA).

Pfizer, which manufactures the epilepsy medicine phenytoin sodium capsules, was fined £84.2 million in December 2016 for charging “excessive and unfair” prices for the medicine. Flynn Pharma was given a fine of £5.2 million.

The CMA found that the price of the epilepsy medicine had increased by 2,600% overnight. The CMA said that Pfizer and Flynn Pharma were breaking competition laws and had abused their dominant positions in the market. The CMA added that it had imposed its highest fine to send a “clear message to the sector”. Pfizer’s and Flynn Pharma’s appeals challenge the CMA’s decision, saying that they have been wrongly identified as ‘dominant in the market’, according to the Competition Appeal Tribunal. The notices of appeal also said that the companies are challenging the way the CMA used the test to identify whether the price for the medicine was excessive. Both companies are asking the Competition Appeal Tribunal to repeal the CMA’s decision and to cancel or reduce the fines.

In December last year, the CMA revealed that before September 2012, Pfizer’s phenytoin sodium capsules were sold under the name Epanutin and the medicine’s price was regulated. However, in September 2012, Pfizer sold the distribution rights of the medicine to Flynn Pharma, which caused the medicine to be de-branded. This meant the medicine was no longer subject to price regulation. Following this, Pfizer continued to manufacture the medicine, and Flynn Pharma continued to distribute it, but at a much higher price.

Philip Marsden, chairman of the Case Decision Group for the CMA’s investigation, said: “The companies deliberately exploited the opportunity offered by de-branding to hike up the price for a drug which is relied upon by many thousands of patients. These extraordinary price rises have cost the NHS and the taxpayer tens of millions of pounds.