



CROYDON EPILEPSY SOCIETY

NEWSLETTER

Winter 2016

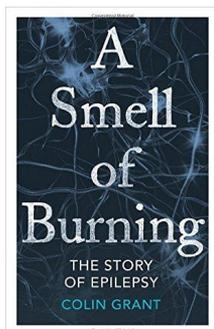
We wish all our members a **Happy Christmas and New Year**. It has been an eventful year with the society moving out of the Len Pyant Centre in West Croydon but we are still receiving regular enquiries through our email and on facebook.

The Croydon tram crash in early November, when 7 people died and 51 were injured, was a great shock to local people. The society would like to offer their support to all those affected by this tragic accident and to send our condolences to those who may have lost loved ones. Most people living in the Croydon area including myself have used the tram at some time and it does affect you personally.

In November, we were contacted by email by the Mental Health Co-ordinator of the Croydon Branch of **Crisis UK**. The charity works with people who are homeless and vulnerably housed and they also support their physical and mental health, some of whom may have epilepsy. If you know anyone who may be homeless especially at Christmas time please contact Crisis on 020 8683 5170, mobile no 07583 063316. Their address is 2 Whitgift Street, Croydon.CR0 1FL. Visit their web site www.crisis.org.uk for further information.

I received an Autumn Newsletter back through the post informing me of the sad death of Pam Joselyn who had worked for the society as a volunteer at the day centre over a number of years. She had retired to Clacton-on-Sea but had kept in touch with the society and will be missed. I am sure many members will remember her with fond memories.

New Book on Epilepsy



There was a new book published earlier in the year." **A Smell of Burning**" by Colin Grant.

The book is written by Colin Grant whose brother Christopher suffered from epilepsy. A "*Smell of Burning*" tells the remarkable story of this misunderstood disorder. How certain people, at a particular moment in their life, start to suffer seizures, often preceded by an aura, of which a smell of burning is one of the most common.

For many years epilepsy was associated with mental illness or even possession by devils. People with epilepsy were forbidden to marry or have children. Many became victims of Nazi eugenics programmes. To this day many people with epilepsy – sixty million worldwide – still live in fear of exposure. However, with the help of charities like **Epilepsy Action** and the **Epilepsy Society** life is much easier for people who are diagnosed now with epilepsy.

Our own charity was contacted this year by a brother whose sister suffered from epilepsy. He was concerned that his family was not wanting to enter her into an arranged marriage due to their concerns regarding her condition. So work still has to be done.

Grant's book traces the history of the condition and the pioneering doctors whose extraordinary breakthroughs finally helped gain an understanding of how the brain works. He tells the stories of famous people with epilepsy like Julius Ceasar, Joan of Arc, Fyodor Dostoevsky and Vincent Van Gogh, and through the tragic tale of his brother, he considers the effect of epilepsy on his own life.

If you are interested in reading this book a copy can be purchased at your local book shop or on-line at:

<https://www.amazon.co.uk/d/Books/Smell-Burning-Story-Epilepsy-Colin-Grant>

A copy can also be obtained through Croydon Libraries, if not available at your local branch a copy can be reserved free of charge.

Fines for drug company for overcharging for epilepsy drug

There has been a number of articles in the newspapers in early December about Pfizer being fined a record £84.2m by competition watchdogs for overcharging the NHS for an anti-epilepsy medication prescribed to thousands of patients. NHS spending on **phenytoin sodium capsules**, rose from £2m a year in 2012 to about £50m in 2013.

Until September 2012 Pfizer manufactured and sold phenytoin sodium capsules to UK wholesalers and pharmacies under the brand name **Epanutin** and prices of the drug were regulated. But Pfizer sold the UK distribution rights for Epanutin to Flynn Pharma that month, which then saw the drug “debranded” or made generic so it was no longer subject to price regulation. The companies then each ramped up the price of the drug overnight. At one stage the price of 100mg packs of the drug jumped from £2.83 to £67.50. The NHS had no alternative but to pay, as epilepsy patients already taking phenytoin sodium should not usually be switched to other products because of the risk that seizure control could be lost. Pfizer is planning to appeal against the ruling.

<http://www.independent.co.uk/news/business/news/pfizer-flynn-pharma-fined-prices-drugs-nhs-cma-a7460266.html>



All Party Parliamentary Group on Epilepsy

This is a Forum for engagement between members of parliament, professionals and the public. The group is headed by Valerie Vaz MP. Input to their Newsletter is provided by a number of groups including Epilepsy Action, Epilepsy Research UK and the Epilepsy Society. The October 2016 Newsletter included comments from these groups:

Epilepsy Action mentioned the risks associated with sodium valproate to women with epilepsy if taken when pregnant. Also the need for more specialist epilepsy nurses.

Epilepsy Action UK is funding 30 research projects in the UK at a cost of over £3.3 million.

The Epilepsy Society mentioned this year marked 21 years of MRI (Magnetic resonance imaging) at the society. MRI has helped them develop a whole pathway from initial diagnosis to working out the cause of epilepsy and whether intervention should be surgical or medical.

<http://www.publications.parliament.uk/pa/cm/cmllparty/register/epilepsy.htm>

Enjoy Christmas

If you are intending to meet friends or family for a meal or drink don't forget all the local restaurants and pubs in Croydon.

After a number of delays in October we saw the opening of **Box Park** in Dingwall Road, next to East Croydon Station. There is a variety of international cuisine available ranging from Indian, Chinese, Spanish, Greek and Taiwanese.

<https://www.boxpark.co.uk/about/>

If you fancy a **trip to London** a large number of museums and galleries have free admission including the Science Museum, the Natural History Museum, the Victoria & Albert Museum and the National Portrait Gallery.

There are a number of exhibitions on at present which have had good reviews if your budget allows, as these do incur charges.

Victoria and Albert Museum "**You Say You Want a Revolution? Records and Rebels 1966 - 1970**" - 10th September to 26th February 2017

This major exhibition explores the era-defining significance and impact of the late 1960s, expressed through some of the greatest music and performances of the 20th century alongside fashion, film, design and political activism.

Please note the entrance to the exhibition is £16.

National Portrait Gallery "**Picasso Portraits**" - 6th October to 5th February 2017

This major exhibition of over eighty works focuses on the artist's portrayal of family, friends and lovers and reveals his creative processes as he moved freely between drawing from life, humorous caricature and expressive painting from memory. The entrance price is £19, £17.50 concession although if you are an early bird the first 100 tickets for every Friday during the exhibition are just £5.

Croydon Epilepsy Society Contact Details

Please contact us by phone or email as we no longer have a Day Centre on a Wednesday morning. Please leave a message on our mobile no or text us and we will get back to you asap.

Further information can be provided by the following national support groups if you need urgent support:

Epilepsy Action www.epilepsy.org.uk Helpline 0808 800 5050
Epilepsy Society www.epilepsysociety.org.uk Helpline 01494 60140

Address: 64 Newlands Woods, Bardolph Avenue, Croydon CRO 9JR.
Mobile No: 07926372711

Email Address: croydonepilepsy@gmail.com

Visit our Facebook Page: www.facebook.com

Web Site: www.croydonepilepsysociety.org

Twitter: Follow us @croydonepilepsy (<https://twitter.com/croydonepilepsy>)

Elected Members

President

Professor F M C Besag, FRCP, FRCPsych, FRCPCH.

Vice - Presidents

Rev G Derriman
Gavin Barwell MP

Honorary Vice - Presidents

Dr P B C Fenwick
Mrs Rosemary Aselford
Rita Richmond

Committee Members

Mr Marco Valencia Chairman
Ms Dawn Gibbons Honorary Secretary
Mr Richard Ruffell Honorary Treasurer
Mr Stephen Marshall

