





CROYDON EPILEPSY SOCIETY

NEWSLETTER

Spring 2018

After starting March with some of the coldest weather in recent years, temperatures gradually rose only to met with another bout of snow! However, as we are start to see longer days and with bulbs and other new growth appearing in our gardens Spring may finally be here. We hope members were able to manage with the heavy snow and cold weather. Despite heavy snow the roads around Croydon seem to manage to stay open and bus services were still available. Commuters travelling by train up to London were not so lucky with many trains cancelled or delayed.

Purple Day is taking place on 26th March 2018. Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness. For Purple Day this year Epilepsy Action is focusing on the vital work of its helpline.



The charity is planning to increase the opening hours of the helpline to include evenings and weekends. The Purple

Day, please support the work of the Epilepsy Action Helpline. You can show the world you care about more support for people with epilepsy with a 2018 Purple day wristband. You can order a wristband or request a pack to run your own Purple day event at epilepsy.org.uk/people or by calling 0113 210 8851.

National Epilepsy Week - Notice of AGM

National Epilepsy Week is taking place from Tuesday 15th May until Monday 21st May 2018. We have decided to hold our AGM on Tuesday 15th May 2018. The event is taking place at the East Croydon United Reformed Church hall in the Beginners Room. The address is Addiscombe Grove, Croydon, CR0 5LP. The start time of the AGM will be at 7.30pm with people arriving from 7.15pm. Both Marco and myself will be hosting the event. Our President, Prof Frank Besag will hopefully be able to join us as well. We will provide drinks and nibbles. We look forward to meeting members and getting your feedback so please join us if you can.

We would also like to remind members that the **2018 membership subscription** is now due. Please find a renewal form included with the Newsletter. Your continued support is vital to keep the society going as we have no longer have council funding. If you are happy to receive an email copy and do not require a postal version as well, please tick the relevant box on your renewal form as this helps us to save both printing and postage costs.

In January, the media reported a case of **driver with epilepsy who had a fit while driving and caused a fatal crash** knowing he shouldn't be driving. In Court, the driver admitted causing death by dangerous driving and was jailed for four years. Anyone diagnosed with epilepsy is told to inform the DVLA or risk a fine. The agency then decides whether to take their licence away. The family of the victim, a 42 year old man who had two young sons, say the law should be changed so that medical professionals notify the DVLA automatically. Drivers can be fined up to £1,000 if they fail to tell the DVLA about relevant medical conditions. Epilepsy sufferers will lose their licence if they have lost consciousness in a seizure. They can reapply if they have not had a fit for year.

In March, the Home Office allowed six year-old Alfie Dingley who suffers from a rare form of epilepsy, to be treated with a **three month trial of cannabis oil**. This followed a strong public support for his case. Members of the all-party parliamentary group for drug policy reform urged the Home Office to allow him to use it. He has to endure up to 30 seizures a day because of his condition. His parents say the oil, which



is currently banned in the UK, helps to relieve them. Due to suffering from a cluster of seizures, he has had to be hospitalised twice since returning from Holland in January, where he was being treated with the substance. There has since been an update with the family meeting the Prime MInister, Theresa May and the mother have been advised to put in an application for longer term use of the drug.

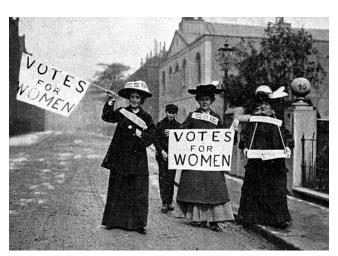
February was the **100th Anniversary of the Representation of the People Act of 1918** that gave some women over the age of 30 the vote for the first time in the UK. Although it wasn't until 1928 until all woman over 21 were given the vote. In November 1918, a separate law was passed - the Parliament (Qualification of Women) Act - which allowed women to stand as candidates and be elected as MPs.

Easter is early this year taking place at the end of March so we would like to wish all our members a Happy Easter.

Dawn Gibbons Honorary Secretary



100th Anniversary of women getting the vote



There is currently a **Votes for Women** display at the **Museum of London** which forms part of the
national commemorations marking
the centenary of the 1918 Act that
gave some women the right to vote
for the first time. Dedicated to those
who campaigned tirelessly for over
50 years to achieve votes for women,
the exhibition features iconic objects
from the Museum's vast Suffragette
collection, including Emmeline

Pankhurst's hunger strike medal. At the heart of the display is a powerful, newly commissioned film that reflects on the contemporary relevance of the militant campaign that continues to inspire, shock and divide opinion.

Emmeline Pankhurst was a key figure gaining intense media coverage of the women's suffrage movement. Pankhurst, alongside her two daughters, Christabel and Sylvia, founded and led the Women's Social and Political Union in 1903, an organisation which was focused on direct action to win the vote.

Frustrated with years of government inactivity and false promises, the WSPU adopted a militant stance, which was so influential it was later imported into suffrage struggles worldwide. After many years of struggle and adversity, women finally gained suffrage but Emmeline died shortly after this. https://www.museumoflondon.org.uk/.../whats-on/exhibitions/votes-women

Useful Information:

Croydon Health Services Neurology Department:

If you are a local support group requesting more information on epilepsy and for a speaker to come to your group to talk about epilepsy and the support available to those who may have epilepsy or be a carer for someone who has the condition. Please email for general enquiries ch-trspecialistmedicine1@nhs.net. The Neurology department includes providing support to those with epilepsy. There are two epilepsy nurses working in the department and they be able to visit your group and provide such a service.

There is a Epilepsy Nurse Hotline/Advice telephone number which is open to GP's and patients (who are already known to the Epilepsy Service).

If you are registered with a Croydon GP and under the care of a Croydon Neurologist and feel this service would benefit you please discuss with your GP who would be able to provide you with the number.

Croydon Age UK offer a range of practical home services for everyone living in the local area, especially those in later life. These include: Handy person, Home Help,Trades Persons List and Nail Care. Charges do apply. Tel no: 0208 683 7120, email homeservices@ageukcroydon.org.uk, www.ageukcroydon.org.uk

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 <u>www.epilepsy.org.uk</u> Helpline 0808 800 5050 Epilepsy Society <u>www.epilepsysociety.org.uk</u> 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/croydonepilepsysociety

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 Honorary Vice - Presidents

Rev G Derriman Dr P B C Fenwick
Gavin Barwell Mrs Rosemary Aselford
Yvonne Green Mrs Rita Richmond

Committee Members

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