

CROYDON EPILEPSY SOCIETY

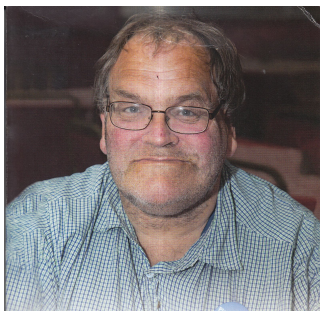
Winter 2019 NEWSLETTER

We are coming to the end of another year with an **election** looming on Tuesday 12th December. The issue of Brexit being the main talking point of the political parties. We urge everyone to vote whatever their political views as depending on the outcome, it may result in significant changes to our relationship with Europe.

In October we were informed of the sad death of **Stephen Aselford**, a prominent Croydon activist for the protection and improvement of the rights of disabled people and a member of the society. He was the son of Rosemary Aselford who helped run the society with Carole Rossington for many years.

The funeral and celebration of Stephen's life was on Friday 25th October which I attended with a number of members of the society. The service was well attended with not only family and friends attending but a number of local councillors including Tony Newman, the leader of Croydon Council. There was a reception afterwards at Ruskin House, South Croydon.

Stephen was an avid supporter of the **Disabled People Against Cuts** and co-founder of Bromley and Croydon DPAC. The society will be making a donation to Croydon DPAC in memory of Stephen. He was also a trustee of **People First**.



His mother Rosemary was able to attend and also his brother David and his niece Jamie who both travelled from Australia.

We were asked to wear red as Stephen had a keen interest and liking of red buses and those attending were offered a model bus from his large collection to remember him. He will be missed by all those you knew him and by the community at large.



Join the Big Conversation

Currently the Croydon Council are asking residents to take part in **the Big Conversation** which asks local residents what we want Croydon to look like in 2030.



The Big Conversation is a groundbreaking resident engagement exercise which gives local residents, businesses and visitors the chance to help shape Croydon's future. The council want to hear the views, concerns and priorities of local people and community groups to help guide council policies and investment over the next decade.

Over the next few months, the council will be exploring six Big Conversation topics – culture at the heart of regeneration; safe and secure communities; caring for each other; decent homes for all; jobs and the economy; and creating a sustainable Croydon.

Visit visit your local library to fill in a postcard/form or complete the survey online with your answers at bigconveration.croydon.gov.uk

Fairfield Halls Reopening



A star-studded ceremony celebrated the **reopening of Fairfield Halls** on the 16th September following a multi-million pound council-led restoration of the iconic Croydon venue.

Special guests included Dame Judi Dench, who reopened the Ashcroft Playhouse in honour of her friend and Croydon-born actress the late Dame Peggy Ashcroft, and Mayor of London Sadiq Khan, who formally opened the building. She unveiled the People's Picture a giant commemorative mosaic by artist Helen Marshall.

Visit <https://www.fairfield.co.uk> for details of the current programme of events.

Anniversary of the Croydon Tram Crash

A civic ceremony took place in New Addington on **Saturday 9th November**, to mark the third anniversary of the Sandilands tram derailment. More than 60 people were injured in the incident and seven people were killed.

The Crown Prosecution Service announced before the anniversary the driver of the tram, Alfred Dorris, from Beckenham, who was expected to be charged with gross negligence manslaughter, but will not be, due to a lack of evidence. Transport for London will also not face charges of corporate manslaughter. The official report by the Rail Accident Investigation Branch concluded that Mr Dorris fell asleep whilst approaching a bend at four times the speed limit just after 6am. TFL has introduced additional safety measures since the crash, including infrared eyeball monitors to alert drivers if they show signs of falling asleep.

Cannabis-based Medicines Update

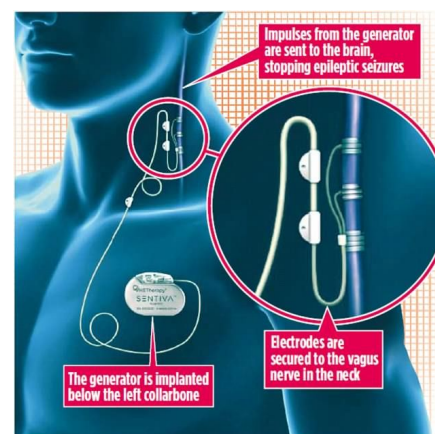
In November it was announced the approval for the NHS to use two cannabis-based medicines in treating epilepsy and multiple sclerosis and was welcomed by campaigners as an “important first step.”

New guidance from the **National Institute for Health and Care Excellence** will allow doctors to prescribe Epidyolex for rare types of epilepsy - Lennox-Gastaut and Dravet syndromes. There are up to 9,000 people who suffer from rare types of epilepsy which Epidyolex has been approved for. However, it did also said that more research was needed on cannabis-based medicines to treat other forms of epilepsy.

Brain “Pacemaker” that stops Epileptic Fits in their Tracks

In June, an article in the Mail On Sunday referred to a “**pacemaker**” that can detect and even stop epileptic seizures that is being used by the NHS for the first time. Simukai Shambira, from Surrey, who endured up to 14 seizures daily, has become the first patient in Europe to be fitted with an implant, and the nine-year old has seen his seizures reduced to a few per week.

The SenTiva device is a game-changer for those who fail to respond to epilepsy drugs. The implant - the size of a £2 coin - is being used by experts at King’s College Hospital in London after being granted approval by the European Commission in April. It uses an advanced type of brain stimulation called **vagus nerve stimulation**, or VNS.



Events to Visit over Christmas:

Top Secret: From ciphers to cyber security

The Science Museum is currently showing an exhibition that explores 100 years of code breaking including artefacts used by code breakers at Bletchley Park during the Second World War. The exhibition runs to 23rd February 2020

<https://www.sciencemuseum.org.uk>

Tutankhamun - Treasures of the Golden Pharaoh

150 original artefacts will be on show at the Saatchi Gallery in London until 3rd May 2020 as part of a world tour. <https://www.tutankhamun-london.com>

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 an 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 telephone number.

The Croydon Carers Support Centre in George Street, Croydon is open to provide support to carers. <https://www.whitgiftfoundation.co.uk/content/carers-support-centre>
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
There is also a Helpline no 0208 686 0066 for general enquiries.

Croydon Epilepsy Society Contact Details

Please contact us by phone or email. 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/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

Yvonne Green

Honorary Vice - Presidents

Dr P B C Fenwick
Mrs Rosemary Aselford
Mrs Rita Richmond

Committee Members

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

