



CROYDON EPILEPSY SOCIETY

NEWSLETTER

Autumn 2017

We have continued to be affected by events at home and abroad with another terrorist incident in London on the tube in September, although thankfully no one was killed on this occasion. However, the hurricanes and storms in America and the Caribbean Islands have caused a lot more destruction and casualties. Followed in early October by the terrible gun attack in America at a music concert in Las Vegas. We offer condolences to all those affected by these tragic incidents.

Epilepsy has also been in the news in September with the **epilepsy drug sodium valproate** and its harmful effects to unborn babies. Please refer to the article below for further details.

There has also been a **change in naming seizures** announced by the International League Against Epilepsy (ILAE). These changes don't mean you have to change the way you talk about your seizures, unless you want to. However, it is important to know about the new names so that if your doctor or epilepsy nurse uses them to describe your seizures, you know what they mean. Please see a summary of these changes listed below.

The society is pleased to have Yvonne Green as a **new Vice-President**. She is the Branch Secretary of Croydon UNISON and we look forward to working with her. She has a family member with epilepsy so is aware of the importance of providing support and advice to those who may need it.

Earlier in the year the Healthy Living Hub on the ground floor at Croydon Central Library had a makeover and has been renamed **Just Be Croydon**.

We all sometimes struggle with making healthy changes such as losing weight, being active, eating healthier, stopping smoking and taking care of your sexual health.

With the help of their new go-to website, there is lots of handy advice and resources to help you to become happier and healthier.

Contact them by email: info@justbecroydon.org or visit the website

www.justbecroydon.org

The society has received a number of **enquiries from local support groups requesting more information on epilepsy** and for a speaker to come to their 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. As I work full-time I am unable to attend such groups.

However, I did some research online and under the Croydon Health Services Neurology section there is an 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.

There was also an enquiry about **local support groups** for those with epilepsy. I was directed to the **Croydon People First** group by a member. The group provides support for those with learning disabilities including those with epilepsy. At present they run a monthly meeting hub including a coffee bar on the first Wednesday of the month from 11am to 2pm at St Michael's All Angels Church Hall, Poplar Walk, Croydon. Due to funding the Wednesday Hub may not continue in 2018. However, the meetings on Wednesday 1st November and Wednesday 6th December will still be taking place. In 2018 they are introducing "Make it Happen" which will provide day out activities. If you are interested in attending please contact Croydon People First on 020 8253 7096.
Email: info@croydonpeoplefirst.org.uk Web: www.croydonpeoplefirst.org.uk

Please continue to contact us if you have any questions relating to epilepsy and we will endeavour to answer them.

Dawn Gibbons
Honorary Secretary

Seizures renamed by the ILAE

In the September issue of Epilepsy Today produced by the national Epilepsy Action there was an article entitled "Seizures renamed". The International League Against Epilepsy (ILAE) has announced new names for seizures and some new seizure types.

In 1981, the ILAE created a classification system for seizure types: a way of naming seizures and putting them into groups. This classification is widely used by healthcare professionals all over the world. The ILAE have now updated the 1981 classification with new names and categories, with the aim of making doctors describe seizures more accurately. The main changes are:

In the old classification, seizures that start on one side of the brain were called partial seizures. These are now called focal seizures.

The new classification splits focal seizures into two groups according to what level of awareness you have during one. If you remain alert and aware of your surroundings throughout, it's called a **focal aware seizure**. **This replaces the old term simple partial seizure, or sometimes an aura**. If your awareness is affected at any time during a focal seizure it's called a **focal impaired awareness seizure**. **This replaces the old term complex partial seizure**.

The new classification has introduced a **new type of seizure** called a **focal to bilateral tonic-clonic seizure**. This is a tonic-clonic seizure that starts in one side of the brain and spreads to affect both sides. **It replaces the old term secondary generalised tonic-clonic seizure**.

Previously, seizures were split into those that started in one side of the brain (focal seizures) and those that affect both sides of the brain from the start (generalised seizures). There was no overlap between the two groups.

The new classification recognises that some types of seizures can be focal or generalised. Examples of seizure types that can be either focal or generalised include atonic, tonic and myoclonic seizures.

For more information visit epilepsy.org.uk/seizures.

Epilepsy drug's safety reviewed over pregnancy risk

Women whose children have been harmed by the epilepsy drug sodium valproate gave evidence to a European-wide safety review in London at the end of September.

The European Medicines Agency will examine whether warnings about risks to unborn babies are strong enough.

About 20,000 babies in the UK alone have been left with disabilities since valproate was introduced in the 1970s.

The medicines regulator said warnings had been updated as more information had become available. Many women whose babies were affected say nobody warned them of the extent of the dangers. Valproate is an effective treatment for epilepsy, bipolar disorders and migraine - and doctors prescribe it because it is the best option for some women.

Instructions for doctors - and, more recently, patient leaflets - say valproate should not be used during pregnancy unless there is no safer alternative and only after a careful discussion of the risks.

Scientific papers as early as the 1980s suggested valproate medicines were dangerous to developing babies. More evidence emerged throughout the 1990s. In 2005, UK patient information leaflets included concerns about delayed development in children. Last year, warnings were also added to the outside of valproate pill packets in Britain.

Medicines watchdog the MHRA said: "It is important women don't stop taking valproate without first discussing it with their doctor."

"The decision to use any medicine in pregnancy requires a careful evaluation of the benefits and risks to both the woman and to her unborn child."

"When considering the known risks of valproate, it is important to remember that untreated epilepsy and bipolar disorder can also carry serious risks."

"As with all medicines, the safety of valproate in pregnancy has been kept under constant review, and as new data have become available, the warnings have been updated."

Information taken from the BBC web site.

Useful Information:

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 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

Rev G Derriman
Gavin Barwell
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
Mr Stephen M Marshall

