

# Epilepsy HERE

Registered as a Charity No. 1079172

Whitstable United Reformed Church, Middle Wall, Whitstable CT5 1BW

Telephone: 01227 274757 e-mail: [herebay@aol.com](mailto:herebay@aol.com)

and at 11, Beaumanor, Herne Bay, Kent Telephone: 01227 360207

Mobile (44) 07435005409

Meetings held Monday monthly (except January & August) at Headway House, Kent and Canterbury Hospital, Ethelbert Road, Canterbury CT1 3NG at 6.30 p.m.

"Coffee Break" at Whitstable United Reformed Church every third Tuesday each month 10.00 a.m. to 11.30 a.m.



Volume 20 Number 2 April/May/June 2019

**Whitstable  
United Reformed Church**  
Middle Wall, Whitstable CT5 1BW

## SPRING CONCERT

**Canterbury Music Makers**

Will play music by favourite British Composers:  
Elgar, Coates, Vaughan Williams, Edward German

Including the first performance of  
"Northern Journeys"  
a Viola Concerto written for the orchestra by our  
Composer in Residence John Pell

Conductor: Steve Wassell  
Leader: Paul Hillier  
Solo Viola: Paul Hillier

**Saturday 30th March 2019  
7.30pm**

Tickets: £7 available from:  
Epilepsy HERE at 01227 360207  
[herebay@aol.com](mailto:herebay@aol.com)  
Or at the door  
Interval Refreshments provided

All Proceeds in aid of  
 and  
 Whitstable United Reformed Church

We are pleased that the Canterbury Music Makers have decided to donate half of the proceeds of their Spring Concert to us and half to the Whitstable United Reformed Church where we have our office. We shall provide the members to look after the door and show those attending where to sit. The church will provide the hall and the refreshments during the interval. Gifts of cakes for the refreshments would be welcomed if you are able to let us have them before the day. Please telephone us on 01227 360207 or 07435005409. We hope as many will come as possible. The cost of entry is £7 at the door.

## If and when!!

In case you are worried that we may leave the European Union without trade arrangements being in place both the Epilepsy Society and Epilepsy Action have information on the website. For our own satisfaction through the good offices of Sir Roger Gale MP for North Thanet we have received a letter from the Department of Health and Social security which includes the following information.

"As Mr. Kendall may be aware, in addition to the existing DoH "no deal" contingency plans involving pharmaceutical companies, we are considering introducing new regulations... to allow the Government to issue a serious shortage protocol.....community pharmacists can, if appropriate, dispense an alternative quantity, an alternative pharmaceutical form, an alternative strength, a therapeutic equivalent or a generic equivalent, as indicated in the protocol without going back to the prescriber.

We are aware that protocols for therapeutic or generic equivalents will not be suitable for all medicines and patients. **In particular, we understand that such protocols would not be suitable treatments for epilepsy** or treatments requiring biosimilar products where the **medicines need to be prescribed by the brand for clinical reasons In those cases patients would always be referred to the prescriber for a decision about their treatment.**" We can only repeat that if you receive any medication for your epilepsy that differs from that which you usually get you should question the pharmacist as to why this is the case.

## Donation from ASDA

We are most grateful to the customers of the Asda Store in Sturry Road, Canterbury who nominated and supported our charity to receive a benefit under their green disc scheme. As a result of this we have received a cheque for £200 which will enable us to maintain and improve our services

Financially supported by  
Ronald Cruickshanks Foundation



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### **National Council for Voluntary Organisations**

We have been members of the NCVO since the early days of our charity when we found the information they provided to be extremely useful and this year they celebrate their centenary having been founded in 1919 just after the First World War where charities had proved to be so valuable. They remained so for the returning service men.

NCVO started as the National Council of Social Service, following a legacy from Edward Vivian Birchall, who died of wounds in France during World War I.

Since then they have continued to support the sector and speak to government in an ever-changing social context. Many established voluntary organisations started out as projects within NCVO, including Age Concern, Citizens Advice Bureau and Community Matters.

To celebrate their centenary they are holding a reception at Windsor Castle to be hosted by HM The Queen and the Chief Executive of NCVO Sir Stuart Etherington has invited our chairperson Monica Kendall to attend on 2nd April 2019

### **April meetings**

At the meeting on 1st April 2019 at Headway House we shall discuss the programme for the next few months. If you have suggestions for whom you would like us to invite to talk please do let us know. We shall be at the Coffee morning at Whitstable United Reformed Church, Middle Wall, Whitstable on Tuesday 18th April 2019

### **May meeting**

Because the first Monday in May is a Public Holiday the meeting at Headway House. Kent and Canterbury Hospital, Ethelbert Road, Canterbury CT1 3NG will be held on the second Monday 13th May 2019

### **Purple Day**

Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. It was started by Cassidy Meghan a young Canadian girl who thought there should be one day a year when everyone could raise awareness and raise funds for epilepsy charities. On March 26th annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness. Last year, people in dozens of countries on all continents including Antarctica participated in Purple Day! We have been associated with the day for several years

This year the Epilepsy Nurses are holding an event in the lobby of the Whitstable and Tankerton Hospital, Northwood Road, Whitstable where they have their offices from 10.00 a.m. to 11.30 a.m. And we will be on hand with our leaflets and information wearing our purple fleecesto mark our support .if you are in the area please come along They hope to be have some purple cakes to mak the day

### **Pregabalin And Gabapentin Have Been Re-Classified As Class 3 Controlled Drugs**

If you have been prescribed gabapentin (Neurontin) or pregabalin (Alzain or Lyrica), it is important to be aware that the law is changing from 1 April 2019 and these medications are being re-classified as controlled drugs.

This will affect the way in which you can get these medications. You will generally have to get a written prescription rather than picking it up electronically. Your GP and local pharmacy will ensure you continue to get the medicines you need. Please remember to order your medicine ahead of time. There will also be some changes to the rules. Some of these are:

Only 30 days' supply is allowed on one prescription

You must collect medicines from the pharmacy within 28 days of the date on the prescription (which is not always the date the prescription was signed)

Any medicine 'owed' to you by the pharmacy must also be collected by that date

For some GP practices, it might not be possible to send prescriptions electronically to the pharmacy. This does not apply if your GP practice uses the electronic prescription service for controlled drugs.

Your GP practice will make these changes before 1 April 2019. Please remember that if you have any existing prescriptions for gabapentin or pregabalin, to collect the medicines before 1 April 2019. Make an appointment with your GP or epilepsy specialist to discuss taking a different version of your medication.