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CROYDON EPILEPSY SOCIETY (./)

Local support for people with epilepsy

CROYDON EPILEPSY SOCIETY

NEWSLETTER

Winter 2014

Another year draws to its close and the society would like to wish all its members a Happy Christmas and New Year.

With the recent budget given by the Chancellor, George Osborne, it appears there could still be hard times ahead with local services continuing to make cuts as councils are put under pressure to meet their budgets for the forthcoming year. There has been a lot of news about the rising use of food banks by families on low incomes. Hopefully, none of our members are in that situation. Please contact us if you are having problems and we will try and provide support and advice.

Congratulations to Marco for taking part in the Lexus Croydon 10k Marathon based around Lloyd Park, Croydon on Sunday 19th October and finishing with a respectable time of 1 hour 15 minutes. Marco raised £150 for the charity and he's feeling a lot

fitter for it!



The society apologies for the lack of an Autumn Newsletter as the committee were busy with fund raising for the Lexus charity run mentioned above and also spending time continuing to update our new web site that was set up earlier this year.
www.croydonepilepsysociety.org (<http://www.croydonepilepsysociety.org.uk/>)

Advice on Travelling Abroad

There has been a number of phone enquiries over the last few months regarding concerns about **travelling abroad if you have epilepsy**. The most important thing is to remember your medication and that you have enough to cover until the end of the holiday. If travelling to Europe, it is good to take your European Health Insurance Card with you. However, don't be put off travelling as it is very rewarding.

In November, I was on holiday travelling to Paris for a week with my partner and then on to New York. It was very interesting comparing these cities. Both are very busy, vibrant places.

In Paris we visited various tourist sites including Disney Paris, the Eiffel Tower and the Pompidou Centre. The Pompidou Centre was opened in 1977 and is named after the former French President Georges Pompidou. Disney Paris was very crowded as unknown to us we didn't realise that there was a public holiday on Tuesday 11th November for the Armistice 1918 Anniversary.

There was slight moment of panic when travelling from Paris to New York when I was told that I couldn't fly out to New York as my ESTA had expired. This is a travel visa

issued by the USA which allows visitors from overseas to enter the country. Apparently mine had expired earlier in the year! However, after the initial shock of being told I couldn't go through customs I was offered the opportunity to renew the ESTA on-line on one of the 2 computers supplied at the air-port. After some delay and a special quick pass to get through security we just managed to catch our plane on time!

In New York we visited a number of famous places with the New York City Pass which we purchased before we went on holiday. This pass included entrance to the Statue of Liberty, the Empire State Building and a number of New York museums including the Museum of Modern Art and the Metropolitan Museum of Art. The Museum of Modern Art contains the famous painting a "Starry Night" painted by Van Gogh. We also had a visit to Central park which has an area called Strawberry Fields with a plaque in memory of John Lennon. John Lennon, the famous Beatle lived in New York until his death in December 1980, when he was shot down just outside his New York apartment.

So a couple of travel tips check for any public holidays when you go abroad and if travelling to the USA make sure your ESTA is up to date as it only lasts for 2 years.

Dawn Gibbons, Honorary Secretary

The Lexus 10k Run 20014 & Fun

When I started attending the Croydon Epilepsy Society centre, in order to help out as a volunteer, I realised how much hard work had gone into the centre in order to keep it active and accessible to the public.

Clearing out and tidying some draws and cupboards we stumbled across some old photographs of the many fund raising events organised by the CES. I was amazed to see how many people were smiling and enjoying those moments because I know first-hand how difficult and stressful it can be to organise a fund raising event.

Dawn explained to me that trying to raise funds for the CES was a major struggle but these types of events helped maintain the centre open and raise awareness of Epilepsy.

So I decided, with the support of Dawn to participate in the Lexus 10k Run in Lloyd Park, Croydon and raise some money for the society.

I registered online in the summer and awaited a confirmation of my shirt number. The run would take place on the 19th of October at 10:15 in the morning. In the mean time I would periodically go to Lloyd Park and attempt to get fit and practice running long distance. I imagined myself as a Sebastian Coe or even better a Steve Ovett and crossing the finishing line to a round of applause at an Olympic game but I soon realised I had a very long way to go before I could even contemplate receiving my first Olympic gold medal.

I was still on the reserve list a week before the run however with the joint effort of

Eric Campbell and Mike Fischer I was given to go ahead to participate in the run.



Doing the run was a great feeling and as I crossed the finishing line I looked up at the official time keeping clock and it read 1 HOUR 15 MINUTES. I was in shock and really surprised. A volunteer presented me with a medal. I had achieved something positive and it felt really good.

It was a great day for a great cause and with the support of Dawn, colleagues and friends, my girlfriend Olga and Dawn's partner Karl and a big hand from Eric Campbell I managed to run 10k.

Will I run it again next year? Of course I will. I have already registered so keep Sunday the 18th of October 2015 free to come and cheer me on or better still...participate and raise money for the Croydon Epilepsy Society.

Marco Valencia

Work Club

The society continues to have enquiries from members who have been made redundant and are looking for work. There is currently a Work Club at the Central Croydon Library on Tuesday and Thursday mornings. The start time is from 11am to 1pm. It takes place on Level 2. There is free computer use and printing. If you are looking for work and need help with your CV, applying for jobs online or help to complete an application form please come along for some support.

It is always difficult starting a new job but when you have a medical condition to consider it can cause added complications and worries.

When my son was diagnosed with epilepsy in his teenage years I had many worrying questions: *"how would ever get a job if he has epilepsy?" "Would he have to declare his conditions to his employer?" and "how much knowledge is there in the workplace to accommodate colleagues with medical conditions?"*

Fortunately with time I have learned that in his particular case having epilepsy has not been an issue and my son has had a few jobs, mainly admin, and only one has had to let him go because of his condition but it is important to know your basic rights if you do have epilepsy and are applying or starting a new job.

According to national organisations such as Epilepsy Action you do not have to tell your employer that you have epilepsy as long as you don't believe it will affect your ability to do your job safely and effectively. This could be, for example, if your seizures are well controlled.

If you don't tell your employer about your epilepsy, and it does affect your ability to do your job safely, your employer may be able to dismiss you. To do this, your employer would have to prove that they have given you the opportunity to tell them how your epilepsy could affect your job and you haven't provided this information prior to starting your new role.

It's a case of being honest with yourself and your new employer. My son declared his condition to all his employers and they all adhered to the Health and Safety Act (1974) which by law obligates employers to provide a safe workplace for him and all other employees. At the same time it is your responsibility that if your epilepsy could cause a health and safety risk to you or your colleagues you must inform your employer and this is Law and part of the health and safety Act, according to Epilepsy Action.

I have met many people who have epilepsy who lead a normal life, which includes employment. Their job roles include administrators, athletes, supervisors, managers, teachers, chefs and musicians. And like many of us they have good days and bad days at work but I suppose what is important is that we feel safe, welcomed and accommodated for. I am 100% sure that the workforce which has epilepsy are not asking for or demanding special treatment but I think an awareness of the condition is important. Knowledge lessens stigma and discrimination and opens up opportunities for everyone.

Article Marco Valencia Source: Epilepsy Action

Sport and leisure activities and Epilepsy

There has also been an enquiry about if it is safe to take riding lessons if you have epilepsy. On further research from the Epilepsy Action web site www.epilepsyaction.org (<http://www.epilepsyaction.org/>) there is a section which gives advice on taking part in a number of sporting activities

The web site states that with the right support and the relevant safety precautions, there is little that someone with epilepsy should need to avoid. Many people with epilepsy have their seizures completely controlled by epilepsy medicine and don't

need to take any greater safety precautions than anyone else. However it is always a good idea to follow the rules and recommendations in terms of safety equipment.

Some people say that when they are active, they are less likely to have seizures. So, for some people with epilepsy, taking part in sport and leisure activities can really benefit their epilepsy. A very small number of people with epilepsy find that doing strenuous exercise increases their likelihood of having seizures.

Members News

In November we received the sad news that Mark Williams, one of our long term members, had died as a result of complications following a fall. In the past, he had helped at the society with sending out our Quarterly Newsletters. We shall all miss him at the society and we send our condolences to his wife Christina and his family.

Renewal of 2015 Older Persons Freedom Pass

If your Older Persons Freedom Pass bears the expiry date 31st March 2015 you should have received renewal letters and forms between the 3rd November and the 9th December. The easiest way is to renew it online: the process only takes a few minutes but if you do not have access to a computer or need help to apply ASC (Advice Services Croydon) are running a number of sessions at venues around the Croydon borough to help you.

These sessions are at Croydon Central Library in Katherine Street, on Friday 12th & 19th December between 10 – 12.00pm.

Age UK Croydon also located in Katherine Street, Croydon have a session on Monday 15th December from 2-4pm. For more information please call their helpline on 0202 86868 0066 - 10am-4pm.

Day Centre Update

We are hoping to continue running the centre on a Wednesday on a regular basis from 11 am to 3pm which will continue to provide a regular drop in service.

When unmanned please email cesociety@btconnect.com (mailto:cesociety@btconnect.com) or phone us and leave a message and we will endeavour to get back to you as soon as possible.

Further information can be provided by the following national support groups when our centre is closed:

Epilepsy Action www.epilepsy.org.uk Helpline 0808 800 5050

Epilepsy Society www.epilepsysociety.org.uk (<http://www.epilepsysociety.org.uk/>)
Helpline 01494 60140

Useful Contacts:

Croydon Carers Centre

The Croydon Carers Centre is based at 12 Katherine Street, Croydon, CR0 1NX

Telephone No: 020 8688 7219. Email: enquiries@croydoncarers.org.uk

Croydon Carers Support Centre

In October 2013, the Croydon Carers Support Centre set up in 24 George Street, Croydon. CR0 1PB

Telephone No: 020 8649 9339 Email: info@carersinfo.org.uk

Computer Courses

If any member is aware of any courses for people with disabilities please contact us with the details. Free internet access is available at any of the Croydon Libraries.

Croydon Epilepsy Society Contact Details

Drop In Centre:

Times are as follows: Wednesday Between 11 and 3pm subject to staff cover

Please feel free to ring, email or call in at the Croydon Epilepsy Centre with any queries. Please leave a message on the answering machine and we will get back to you asap.

The Len Pyant Community Centre, 17 Elmwood Road, Croydon CRO 2SN.

Telephone: 020 8665 1255

Email Address: cesociety@btconnect.com (<mailto:cesociety@btconnect.com>)

Visit our Facebook Page: www.facebook.com (<http://www.facebook.com/>)

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Elected Members

President

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

Vice - Presidents Honorary Vice - Presidents

Rev B Pavitt Dr P B C Fenwick

Rev G Derriman Rev Canon R S White

Mrs R Richmond Mrs Rosemary Aselford

Committee Members

Position Vacant Chairman

Ms D Gibbons Honorary Secretary

Mr R Ruffell Honorary Treasurer

Mr S Marshall

M r M Valencia

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