

## West Lothian Support Group Newsletter - September 2015

We hope you have enjoyed summer and look forward to seeing you at group meetings. This newsletter covers activities from September to the Christmas Lunch; the next will be posted in January 2016. In the meantime, updates with news and information on events will be emailed as we hear of them, with copies available at meetings. If you have email but get our letters by post, please let us have an email address to keep you more regularly informed, and save significant cost. Send a message to [wlsupportgroup@aol.com](mailto:wlsupportgroup@aol.com). Your email address will not be given by us to anyone.

The venue for meetings is the Community Education Centre, Strathbrock Place, Uphall, EH52 6BN, at 1.00 to 3.00 pm on the last Wednesday of the month. Your gifts are still very welcome as prizes for the raffle at all group meetings.

### Wednesday 30<sup>th</sup> September - Group Meeting

We will welcome our guest speaker, Wendy Doran, who is both a historian and a walking tour guide. She is a graduate in history from Edinburgh University and a post graduate in Scottish history from Glasgow University. She has written several text books and taught history in Scotland's secondary schools in for 28 years. She now works for Mercat Tours in Edinburgh, leading walking tours of the Royal Mile and Castle. Wendy will give us an illustrated talk on the Secrets of the Royal Mile, covering some of the hidden gems and fascinating stories of this historic area which are not all in guidebooks. The closes and courtyards have had a chequered history over the years. We can look forward to Wendy revealing their secrets with humour and enthusiasm.

### Wednesday-Thursday 7<sup>th</sup> – 8<sup>th</sup> October Independent Living Scotland at SECC, Glasgow

This exhibition's 100 exhibitors display a wide range of products and organisations that aim to ease living with long term conditions and that help carers. There is also a full programme of seminars and lectures. Admission is free to the public as well as involved professionals. You need to register online at <http://www.independentlivingscotland.org> or phone 0141 576 3158.

### Wednesday 7<sup>th</sup> October "October Forum" St Mungo Museum, Glasgow.

The agenda for the forum is yet to be finalised, but will include discussing the new Scotland team structure and plans for the core offer – what Parkinson's UK should be providing – looking forward five years to 2020. The new development volunteer roles will also be covered and there will be a campaigns and media update.

### Wednesday 28<sup>th</sup> October Group Meeting

Tanith Muller is very kindly taking time out from her important and absorbing work as campaigns and policy officer at Parkinson's UK Scotland; she keeps a very close eye on developments at Holyrood and Westminster and on activity by the Scottish Government. Maintaining links with politicians and civil servants, organising lobbies and campaigning all help to make sure that the voices and needs of the 10,000 people with Parkinson's in Scotland, and their families and carers, are heard when policies are in concept, development and consultation stages.

### Wednesday 25<sup>th</sup> November Group Meeting

Two members of Leith Churches Together will talk about their recent experience with a team running a Reflective Spaces in Schools event at a local primary school. It involved turning the gym into a quiet space and setting up simple 'reflective stations'. One activity, Fizzy Forgiveness, asks the young student to think about things that they want or need to say sorry for, and then to drop a soluble Vitamin C tablet into a tall jar of water as a symbol of that sorry prayer. The tablet slowly dissolves, symbolising the clean start that forgiveness offers. The purpose is to develop an ability to keep calm and to think deeply; it is not an exercise in evangelising.

### December 4<sup>th</sup> Festive Concert, Greyfriars Church, Edinburgh at 7.00 pm

This year's concert is the fourth held to raise funds for Parkinson's research in Scotland. Tickets are now on sale at £10-00, online at <http://www.parkinsons.org.uk/content/festive-concert-edinburgh>, or Leah Cranney on 0344 225 3724 or email [scotlandfundraising@parkinsons.org.uk](mailto:scotlandfundraising@parkinsons.org.uk). Accompanied children under 12 go free. Full details of the programme will be available at group meetings in October and November, and included in email updates.

### Wednesday 9<sup>th</sup> December Christmas Lunch

Since it has been consistently enjoyable we have booked our lunch at Uphall Golf Club. It is a popular venue, so we are limited to 40 places. Please let us know by 15th November at the latest, if you can come and how many places you would like. Please put your name down on the sheet at the September or October meetings, or telephone 01501 762510 or email [wlsupportgroup@aol.com](mailto:wlsupportgroup@aol.com). Several weeks before the lunch you will be contacted to give your choices from the menu. The lunch and a drink from the bar will be provided free from the group's funds.

**Deep Brain Stimulation – Scotland’s Postcode Lottery** Speaking out against the lack of provision in most of Scotland, Katherine Crawford, Parkinson’sUK director in Scotland, said: "Around 30 people with Parkinson's in Scotland would be likely to benefit from DBS surgery each year. The creation of a sustainable National Service in Glasgow would significantly improve access to the treatment for every suitable candidate in Scotland and provide a specialist centre that delivers improved outcomes for people with Parkinson's." People like Les Macleod, 59, from Arran, who said that having DBS six years ago had given him his life back, are lucky to live in West Scotland.

**Drug Approved for Liver Treatment Promising Results for Parkinson’s** Dr Arthur Roach, Director of Research and Development at Parkinson’s UK, which part-funded the Sheffield University study, said: "There is a tremendous need for new treatments that can slow or stop Parkinson’s." Because of this urgency, the testing of drugs like ursodeoxycholic acid (UCDA), which are already approved for other uses, is extremely valuable. It can save years, and hundreds of millions of pounds. "This type of cutting-edge research is the best hope of finding better treatments for people with Parkinson’s in years, not decades."

**New Direction in Parkinson’s Treatment.** Currently, the symptoms of Parkinson’s are treated using drugs which do not address the underlying cause of the disease, or slow down progressive neuro-degeneration. The BrainMatTrain project has funding of €4 million to develop new technology to target both the inflammatory and neurodegenerative phases of the disease. This research hopes to develop the first disease-modifying therapy for Parkinson’s which could slow down the progression of the disease rather than offering a measure of control or relief of symptoms. The consortium is led by a team based in Galway with researchers from 6 countries in Europe.

**Chocolate Trials at Dresden University of Technology** This study evaluates plasma concentrations of pharmacologically active constituents of chocolate and their effects on motor and non-motor symptoms of Parkinson's. After a week of abstinence from cocoa-containing products, volunteers with Parkinson’s will receive either dark (85% cocoa) or white (0% cocoa) chocolate. After a week of chocolate consumption, patients will then cross over to white or dark chocolate, respectively, and take the corresponding chocolate product for another week. Blood samples will be taken at baseline, week 1 and week 2 to examine plasma concentrations of pharmacologically active constituents of chocolate at all three time points. Moreover, patients will be clinically examined for motor and non-motor symptoms at all visits.

**Neuroelectrics** has developed a wireless, easy-to-use technology that can monitor your brain activity (through EEG) and stimulate it while you are playing games in order to treat different pathologies, such as chronic pain, depression and for stroke rehabilitation. The helmets (which may remind you of Soviet cosmonauts) are mainly used in laboratories and hospitals but they can also be given to patients to take home for stimulation therapy remotely prescribed, monitored and adjusted by doctors, or for medical research staff to monitor brain activity at a distance. The Spanish company’s office in Massachusetts is working with the Michael J Fox Foundation to see if it can flag early stage development of Parkinson’s.



**A Generous Offer** The Carony Classic car wheelchair system eliminates lifting when transferring a person between wheelchair and car. The passenger seat is replaced by the Carony seat. When the passenger door opens the seat is rotated sideways and the driver pulls the Carony onto a chassis which becomes the wheelchair. At the end of the drive, the process is reversed. The system is suitable for any car with sufficient head room. It is nearly new and is free to anyone who needs it. A new system’s price can be £3,000. The only cost would be collection from Edinburgh and fitting it into the new owner’s car using an auto-adaption specialist. For further information, please phone Tim Smith (a recent carer for a Parkinson’s person) on 0131 343 6936 or 07780 991 343.



## Dates for your diary in 2016

Wednesday 27 <sup>th</sup> January	Group Meeting Uphall
Wednesday 24 <sup>th</sup> February	Group Meeting Uphall
Wednesday 30 <sup>th</sup> March	Group Meeting Uphall
Wednesday 27 <sup>th</sup> April	Group Meeting Uphall
Wednesday 25 <sup>th</sup> May	Group Meeting Uphall
Wednesday 29 <sup>th</sup> June	Group Outing

Annual Review + Quiz

We have still not confirmed guest speakers, so please tell us about speakers and topics you would like to hear.

Your suggestions welcome