

## WEST LOTHIAN SUPPORT GROUP

November update 2017

### Group Meeting Wednesday 29<sup>th</sup> November

Avril Clerkson, the speaker we had planned is, unfortunately, unable to attend. Linda Donoghue, who runs our fitness classes has very kindly offered to help. She will hold a taster session demonstrating exercises that can be done at home, seated and standing. Her diary is very full, so we will change the meeting's order, starting with Linda at 1.00. Raffle, announcements and tea/coffee will follow her. Shona Lawson, our Parkinson's local adviser will be at the meeting ready to help with questions on benefits, and entitlements.

### Christmas Lunch

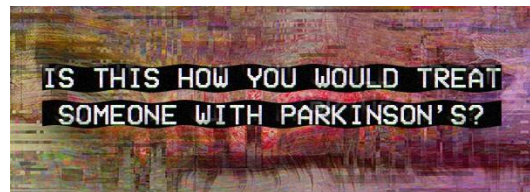
If you are joining us on the 13<sup>th</sup> December, at 12 noon for 12.30, please remember that this year we have changed the venue from Uphall to:

The Almondvale Suite  
Livingston Football Club  
Livingston, EH54 7DN  
Telephone 01506 412232

Throughout Livingston there are many signs to Livingston Football Club' stadium.

### Petition the Government to get a grip on PIP.

Westminster still runs Personal Independence Payment (PIP), Holyrood has no power to change what many feel is an unfair and unthinking attitude to people with Parkinson's. Assessments take little if any account of the facts that the condition is progressive and fluctuates.



Phil Reynolds, Senior Policy and Campaigns Adviser at Parkinson's UK, is organising a petition to the Minister for Disabled People, Health and Work. It reads:

*Please protect people with Parkinson's from losing this vital support by automatically transferring them to PIP if they currently receive high-rate or long-term DLA awards.*

To sign the petition click [here](#) - it only takes a moment. By November 16<sup>th</sup> nearly 24,000 people had signed; the target is 30,000.

### Parkinson's UK Campaign Network

If you would like to be active on behalf of people with Parkinson's and their carers why not join the 9,000 members of the network? You will be given a campaign action for you to take, usually each month. Examples include:

- contacting the Government, your local decision maker or service planner to support a campaign or to resolve a problem
- sharing your experiences
- completing a survey
- joining forces with others to bring about change

The feeling that you are helping to make a difference can often be therapeutic. To join the network or find out more click [here](#)

### **Side by Side Course for Carers.**

This course has been warmly appreciated as a comprehensive guide to all aspects of Parkinson's for carers and those who know they will soon be facing life as a carer. Expressions of interest and your questions about the content are invited now for the 2018 course, which will be held in the spring. The location will be Uphall Community Centre, and the dates will be confirmed once arrangements have been made for the nurse specialists, physio, occupational and speech therapists, Parkinson's Local Adviser and others who deliver the course.

### **Volunteers for Parkinson's Voice Development**

This initiative is a chance to help those affected by Parkinson's. Two sessions to find out more have now been announced. In Edinburgh on Thursday November 23<sup>rd</sup> at the Scottish Council for Voluntary Organisations (SCVO) at Hayweight House, 23 Lauriston Street, EH3DQ. In Glasgow on Thursday November 30<sup>th</sup> at the Health and Social Care Alliance, Venlaw Building, 349 Bath Street, G2 4AA. At each session, refreshments will be available from 10am with the session starting at 10.30am and running through until about 2.30. Lunch will be included. The aim is to involve people with a wide range of backgrounds and those at every age and every stage of Parkinson's. The work could involve being part of a consultation group to give your views on how changes in Scottish Government policy might affect people with Parkinson's and their families, and working with us to raise issues in the media, and with councillors MSPs, MPs and officials.

We are also looking for people to join the Parkinson's Excellence Network in Scotland to work alongside health and social care professionals in the network to identify service improvement issues and to take forward improvement projects. To register interest, or for further information, contact Mary Ellmers, Service Improvement Adviser: [mellmers@parkinsons.org.uk](mailto:mellmers@parkinsons.org.uk), phone 0344 225 3723 or Tanith Muller, Policy and Campaigns Manager [tmuller@parkinsons.org.uk](mailto:tmuller@parkinsons.org.uk) phone 0344 225 3726

### **Opportunity for you to take part in a research project exploring visual hallucinations**

Shannon Dickson at the University of Edinburgh is looking to better understand the mechanisms behind visual hallucinations in Parkinson's. It is thought that visual hallucinations could result from changes in attention and higher level thinking processes. Volunteers will make a one-off visit, lasting up to two hours, to the psychology lab at the University of Edinburgh's main campus. At this session you will complete a sequence of questionnaires and tasks on a computer. For more information, please download the [information sheet \(PDF, 383KB\)](#). The researchers need 10 people with Parkinson's over the age of 18 and 30 people without Parkinson's as a control group. Please contact Shannon by email [s1408274@sms.ed.ac.uk](mailto:s1408274@sms.ed.ac.uk) or phone (07543 634588) before 26 February 2018.

### **Congratulations to Edinburgh Branch Trio**

A joint paper by three members - Alison Williams, Ken Bowler and Bill Wright has been accepted for publication by the **Journal of Regenerative Medicine**. It is entitled: *Adventures with Parkinson's: empowering Parkinson's patients to become active partners in research and treatment*. The Journal's introduction states: Members of the Edinburgh Branch of Parkinson's UK are challenging the common cultural perspective that medical care is simply given to patients by doctors. Instead, they have found that promoting events and interactions between researchers, medical professionals and people with Parkinson's disease has led to active partnerships that improve treatment, impact research and empower individuals. Building these new relationships and taking an active approach to one's own wellbeing benefits everyone involved and enriches society as a whole.

The publisher, Future Medicine, has arranged for the article to be viewed by members on line for free at their website: <https://www.futuremedicine.com/doi/10.2217/rme-2017-0030>.

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