

WEST LOTHIAN SUPPORT GROUP NEWSLETTER April - June 2015

Hello All,

This letter covers the period up to our annual outing on Wednesday 24th June. The next will be sent in September. In the meantime, if you have given your email address, we can send you relevant updates, news items and information when we hear about them. If you come across something that might interest others in the group why not share it?

Saturday 25th April Group Coffee Morning 10.00 to 12.00



Our main fundraising activity for the year is the coffee morning on Saturday, April 25th in Uphall at the South Church. Proceeds will go to research into Parkinson's carried out in Scotland. If you are able to help make this a success, please use the enclosed form to tell us how you can contribute – maybe with home baking, or crafts or prizes for the raffle and tombola, or looking after guests on the day. Before the day you can help by selling tickets or placing posters at local shops, library, surgery, etc.. Parkinson's Awareness Week this year is, incidentally 20th to 26th April.

Wednesday April 29th Group Meeting

Our guest, Anne Chilton, Joint Head of Professional Practice at Relationships Scotland, received very favourable feedback at a recent Side-by-Side course for carers. She will give a general talk about the organisation, (www.relationships-scotland.org.uk), and on the availability of competent counselling services. These are not only for couples, but take in grandparents, parents, teenagers and children. Many of us, living with a progressive, incurable condition, their carers and others close to them, life will call for sensitive adjustments to previous attitudes and expectations. While a few of us manage these effortlessly, and most can work at and reach a solution, some will need qualified assistance. This should come as no surprise to anybody whose relationship with their parents has changed over time. The Parkinson's UK website holds plenty of information on this topic www.parkinsons.org.uk/content/relationships-and-family-life

Wednesday May 27th Group Meeting

We are waiting to hear if Wendy Carle Taylor is able to repeat the very successful group singing session she led last year, and hope to confirm arrangements at Coffee Morning and on the 29th at this month's group meeting.

Wednesday June 24th Annual Day Out

Guided Tour of the Centre for Regenerative Medicine then Lunch and a visit backstage at the Brunton Theatre



The coach will leave from the Uphall community centre at 10.15 a.m. and return at 4.00 in the afternoon. The first stop will be at the laboratories of the Centre for Regenerative Medicine where research into Parkinson's is a significant part of their work and they are very happy to explain their aims, methods and progress. Dr Tilo Kunath has very kindly offered to organise our visit. On arriving we will be offered coffee and then have a short presentation on the Centre's work and an explanation of the areas we will be seeing. Our party will be divided into groups of 10, each led by a member of the laboratory's staff.

Our host, Dr Kunath, leads a team that is part of an international consortium whose aim is to bring cell therapy for Parkinson's from the laboratory to the clinic. He is also working with cells from people with Parkinson's. These are processed and used to produce nerve cells similar to those that die in the brain of Parkinson's patients. Growing the cells in a dish enables the team to observe the formation of protein aggregates, identify the behaviour of the protein that damages cells in patients, and also to use them to screen for drugs that can interfere with this process and prevent cell death.

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After our visit, at around 12.30, the coach will take us five miles to the Brunton Theatre in Musselburgh where we have arranged lunch at the Bistro. To follow the meal we will have a short backstage tour, seeing how a modern theatre functions. We may also be able to watch a ballet company's rehearsal; this is to be confirmed.



As before, the group's funds will cover all costs. To reserve places, please email wlsupportgroup@aol.com or 'phone 01501 762510 or put your name down on the sheet circulating at the April and May group meetings. If you wish to travel by car, there are plenty of blue badge spaces close to the entrances at both destinations, and I will prepare a route map from Uphall. The lunch menu will be at the May group meeting or sent to you to choose from in early June.

Support Group Developments – Exercise Classes and Additional Days Out

Feedback from the seated exercise session led by Judi Samson at the March meeting was very positive. We have started discussing Pilates-based exercise classes, with some individual guidance as well, run by and for our group. The cost seems affordable even if the classes are provided completely free to group members. It is unusually opportune to have found an instructor who lives nearby, has a family interest in Parkinson's and is fully qualified. If you are interested, please let a committee member know your thoughts on preferred time, frequency and venue.

Often, destinations that we look at for the annual day out will appeal to smaller groups: a minibusful or up to, say, 10. For example, the visitor centre at the Queensferry Crossing would appeal strongly to some members, but perhaps less to others, who would prefer a guided tour around a firm that designs, makes, reconditions and sells cashmere clothing- all on one site. If the idea of additional trips interests you, or you have an opinion on the extent to which the group should subsidise them, please contact one of the committee members.

Friday April 10th to April 24th open 11am to 5 pm Exhibition of Art by People Living with Parkinson's

This has been organised by the Parkinson's Nurse Service and Art in Healthcare and is held at St Mary's Cathedral, Palmerston Place, Edinburgh. The aim is to improve public awareness of Parkinson's. It also demonstrates how enjoyable life continues after diagnosis.



21st April to 4th May Norman Yarrow's Transcaledonian Walk

Those of you who were at the meeting in January will remember hearing Norman's wife Carol.

To make a donation, <https://uk.virginmoneygiving.com/normanyarrow>

To follow Norman's progress towards his £100,00 goal, <https://normansconquestwalk.wordpress.com>

For information on joining the walk, nmyarrow@aol.com

Wednesday April 22nd The Edinburgh Parkinson's Lecture

This year's lecture, "The battle to beat Parkinson's: the end of the beginning", is given by Professor Patrik Brundin who has 30 years' experience working on neurological conditions and is Associate Director of Research at Van Andel Research Institute, in Grand Rapids, Michigan. There is no charge, but you must have a ticket. See www.edinburghparkinsons.org/research-interest-group/ or 'phone Mrs Pat Stewart 0131 449 705. The venue is the Royal College for Physicians, 9 Queen Street, Edinburgh. Doors open at 6.30 and the lecture starts at 7.15.

Finally, please email wlsupportgroup@aol.com with any item you wish to share with the group. Without your specific request it will not be credited or identified with you. Naturally, I'll acknowledge and thank you.

With best wishes,

John Ormerod