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UTTLESFORD SUPPORT GROUP
NEWSLETTER/INFORMATION SHEET, April–May 2018
Website: www.parkinsonsuttlesford.org.uk

HAPPENING LOCALLY

The meeting scheduled for 14th February in Saffron Walden, with entertainment from Chris Bishop, had to be cancelled at very short notice indeed. The Support Group committee would like to apologise to all those who tried to attend. On a brighter note, the 14th March Walden meeting, with Mark Start of the Tourist Information Centre, did take place and was well received. Meanwhile the Dunmow meeting on 21st March was well attended; 14 members heard a presentation from Lorraine Chilton, Parkinson's UK Volunteer Coordinator for our area.

The Group continues to raise funds for action against Parkinson's Disease nationally – recently a further £1,500 was submitted to Parkinson's UK.

MEETINGS COMING UP

- The next Saffron Walden meeting will be at the Jubilee Gardens on Wednesday 11th April, 2-4pm, when there will be a talk by librarian Martin Everett about the [Town Library](#), which contains more than 25,000 volumes, and is a major resource for the study of the Victorian and Edwardian periods.
- The next Great Dunmow lunch meeting will be on 18th April at Banks Court, 12am–2pm.
- Wednesday 16th May will bring the eagerly anticipated river cruise! The trip comprises a two-course lunch at the Waterside Inn, Ware (where there is free parking), followed by a 2.5-hour cruise along the River Lee to Stanstead Abbots, passing through a nature reserve. Restaurant and boat are both fully accessible. The boat leaves from the pub and has two toilets on board, one with wheelchair access. Members/carers to pay £10, non-members £20. Individuals to pay for own drinks at pub & on board. Arrive at the Waterside Inn at 11.45 for 12.00 lunch. The Uttlesford Book-a-Ride Minibus will be arranged for those who prefer not to drive.
- Wednesday June 13th June sees the group's popular annual garden party, which will take place at Brackendale House. Further details in the next newsletter.

STREET COLLECTION

The next Saffron Walden street collection will be held on Saturday 21st April. Please email any offers of collectors to Kate Riley: rileyca@eldoret64.plus.com.

PARKINSON'S IN THE NEWS

- A new quality standard published in February by the National Institute for Health and Care Excellence (NICE) states that people with Parkinson's should have access to specialist services including physiotherapy. NICE says people with Parkinson's should be referred to physiotherapy, occupational therapy or speech and language therapy if they have problems with: balance, motor function, activities of daily living, communication or swallowing. The NICE standard has been welcomed by physiotherapists' professional organisations.
- Many people have been shocked by news reports that a man with Parkinson's was ordered out of a branch of Halfords in Stoke-on-Trent because of his 'funny walk', which was interpreted by staff as 'acting suspiciously'. Halfords has since apologised for the incident but it has prompted many other people with Parkinson's to come forward and report similar experiences in shops and other public places. Parkinson's UK says, "*There are too many cases where people are mistreated in shops and venues because of their Parkinson's. This is not acceptable. It's time for a change.*" It called on businesses whose staff come into contact with the public to sign up for Parkinson's awareness training.

FEATURE: PARKINSON'S AND THE TANGO!

Dancing has often been promoted as an activity to help fight Parkinson's disease. There is particular interest in tango, for which studies have been done showing benefits for fatigue, activity participation and quality of life. [See one academic paper assessing this research – [Lötzke et al. BMC Neurology \(2015\) 15:226.](#)] Kate Swindlehurst, who lives in Cambridge has recently written a book, *Parkinson's & the Tango Effect: My Year on the Dance Floor*, which tells the story of the remarkable impact of Argentine tango on her own experience of the condition. Kate writes...

"How does it work? Tango demands posture, balance, confident stepping and turning, changes in speed and direction, particularly difficult but also particularly beneficial if you have Parkinson's. Even more challenging, there isn't a set sequence of steps. Argentine tango is improvised, relying on unspoken communication between the partners in the embrace. This can be a profound emotional experience and a powerful counter to feelings of isolation. It's fantastic to be part of a tango community. And then there's the wonderful music!

"Research has shown the benefits of dance for people with Parkinson's. Some studies suggest that Argentine tango may be the most effective dance, especially for its impact on mood and quality of life. I'm convinced the tango medicine has helped me keep the Parkinson's in check. More recently, deep brain stimulation (DBS)

has had spectacular results – but that's another story!"

More details are available from the website of Unbound Books (<https://unbound.com/books/tango/>) where it is also possible to support Kate in getting her book published.

RESEARCH

- International research, led by Cambridge scientists, suggests that excess levels of calcium in brain cells may be responsible for the formation of 'toxic clusters' found in Parkinson's Disease. This could mean that *calcium-blocking drugs*, which are already in widespread use for the treatment of heart disease, could play a role in Parkinson's treatment. Parkinson's UK says: 'We've known for some time that too much calcium or too much alpha-synuclein – the main protein involved in Parkinson's – causes problems for brain cells affected in the condition. This study is interesting because it's the first time research has shown that there may be an interplay between alpha-synuclein and calcium inside cells, which if disturbed, may cause the damage that ultimately leads to brain cell death'.
- Stem cell therapy, also referred to as cell replacement therapy, is increasingly seen as offering a way forward for Parkinson's treatment. A short article updating us on the current state of research has been published by the Cure Parkinson's Trust: <https://www.cureparkinsons.org.uk/news/stem-cell-therapies-for-parkinsons-current-research>

YOUR CALL

I'm always happy to hear from members with ideas or news items or suggestions for ways in which the newsletter might be improved. In particular, it would really help to have your views on the following points.

- Would you like the newsletter to be longer *or* to be published monthly? (It is bimonthly at present.)
- Are you getting the newsletter by post? If so, please can we send it by email instead?
- Do you not want to be sent this newsletter at all? Please let us know if you want to come off the circulation list.

Paul Chinnock

Parkinson's UK membership: if you are not already a member, we do encourage you to join. Please ask for a form. The fee to join is £4 a year, with an extra £6 a year to join the Uttlesford Support Group.

TRANSPORT: *If you wish to attend a meeting but can't do so because of transport problems – please contact a member of the committee; we will do all we can to find a way to get you there.*

PARKINSON'S NURSE COVERING UTTLESFORD: *Vivienne Kavanagh 01279 621924 or 07778 934669. Unfortunately due to temporary disablement, Viv Kavanagh is currently unable to offer her clinic sessions, but she is still available to give advice over the phone.*

LOCAL ADVISER (formerly Information and Support Worker): *Carol Jacobs 08442 253778.*

Uttlesford Committee: **Chairman – to be appointed;** Secretary, Judy Millward (01763 838742); Donations to the Treasurer, Tony Leek, Richmond House, Mount Pleasant, Hundon, CO10 8DW (01440 786599); Joint Outings Coordinators: Sheila Bricknell (01799 219078) and Mary Woolhouse (01799 530155); Representing Dunmow members, Val McGregor (01371 870296); Membership & Welfare Officer, Janet Crofts (01223 893619); Fundraising Officer, Kate Riley (01799 530350); Speaker organiser: Pat Lodge (01799 500255); Newsletter editor: Paul Chinnock (01799 522570).