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**UTTLESFORD SUPPORT GROUP**  
**NEWSLETTER/INFORMATION SHEET, April–May 2019**  
[www.parkinsonsuttlesford.org.uk](http://www.parkinsonsuttlesford.org.uk)

### SINEMET SUPPLIES

As previously notified by e-mail, the manufacturers of Sinemet have stated that two of their products are likely to be unavailable for several weeks from mid-March (Sinemet 25/250mg 10x10 tablets and Sinemet Plus 10/100mg 10x10 tablets). Alternatives are available. Users of Sinemet should plan ahead and discuss the situation with their doctor or pharmacist.

### LOCAL NEWS

- Nicola McQueen, one of two Parkinson's nurses based at Addenbrooke's Hospital, came to talk with us at our February meeting in Saffron Walden. She gave a very useful and sympathetic talk and answered many questions from our members. The nurses' responsibilities include visiting all inpatients with Parkinson's and checking that staff in the Emergency Department and on the wards are aware of the importance of receiving medicine at the correct time. This includes placing blue clocks with timings by the beds and allowing patients to self-medicate when appropriate. Nicola works closely with the consultants and although she cannot visit people in their homes she can give advice by phone to those people who see consultants based at Addenbrooke's. If you have a planned admission to Addenbrooke's you can contact her beforehand to introduce yourself. Her telephone number is 01223 349814.
  - Do remember that the Parkinson's Nurse for Uttlesford is Viv Kavanagh and the Support Officer is Carol Jacobs. They can be contacted by phone (Viv - 01279 621924 / 07778 934669; Carol - 08442 253778). If anyone is having problems contacting them please let the committee know.
- The group's committee is trying to find another Dunmow representative. Val McGregor who has done a sterling job in this role is finding it increasingly difficult to get to meetings. It is important that the Uttlesford Group serves all its members including those at the Dunmow 'end' of the district. The lunch meetings in Great Dunmow are an important part of our activities. Do come along if you can.
- Parkinson's Awareness Week (10-16<sup>th</sup> April): we have a collection in Saffron Walden during the week on Saturday 13<sup>th</sup> April. Please let Kate Riley know whether you will be able to help (by holding collection boxes for an hour or more) and what your preferred time of day would be.

### FUTURE MEETINGS

- Wednesday 10<sup>th</sup> April, Jubilee Gardens, 2–4pm: Cllr Paul Fairhurst, Saffron Walden Town Mayor.
- Wednesday 8<sup>th</sup> May, Jubilee Gardens, 2–4pm: Paul Warner, Trustee of Parkinson's UK.
- **Annual Garden Party**: we are delighted that Vivian Falk has once again agreed to host the Garden Party which will be on Tuesday 18<sup>th</sup> June at Brackendale House, Saffron Walden. Further details available soon.
- The **Annual Outing** will this year be to the Botanic Gardens in Cambridge on Wednesday 10<sup>th</sup> July. Further details available soon.
- Monthly Saffron Walden meetings will continue at the Jubilee Gardens every *second* Wednesday in each month. We are hoping to bring you a range of interesting speakers!
- Monthly Great Dunmow lunch meetings: every *third* Wednesday, Banks Court, Noon–2pm.
- Christmas Lunch has been booked at the Saffron Walden Golf Club for 9<sup>th</sup> December.

## NOT SO FAR AWAY...

Some of our members (those in the northwest of Uttlesford) are within striking distance of **Royston**, where Parkinson's UK is running a series of events.

- The 'Positively Parkinson's Café' takes place at 10am on the last Tuesday of every month at the Jollie Postie, 2 Baldcok St, Royston SG8 5AY. Details from Julie Wilson: 07500 097222 or [jmwilson@parkinsons.org.uk](mailto:jmwilson@parkinsons.org.uk).
- Julie Wilson is also the contact for information about PRIM (Parkinson's Royston Independent Movers) – an exercise class held at the **Royston** Leisure Centre every Thursday at 1.30pm.
- A 10-week dance class for people with Parkinson's is already under way at the Coombes Community Centre, **Royston** (11am-12.30pm on Wednesdays). It is run by [Imagination Arts](#) who should be contacted for details: 07714378887 [hannah.imaginationarts@yahoo.com](mailto:hannah.imaginationarts@yahoo.com).
- Also in **Royston**, a research workshop is being held 1.30-3.30, Friday 5<sup>th</sup> April at the Coombes Community Centre, Burns Road SG8 5PT. It's a chance to hear about the latest developments in research. *Places must be booked in advance* from the Parkinson UK's Research Events Officer on 0207 9639315.
- The **Cambridge** Branch of Parkinson's UK is holding its annual Tulip Fun Run on Sunday 14<sup>th</sup> April to mark Parkinson's Awareness Week. The Fun Run route is approximately 4 miles (7km), starting at the David Rayner Building at Scotsdale's. Details from the Cambridge Branch [website](#).
- Paul Mayhew-Archer (a writer, producer and script editor who co-wrote 'The Vicar of Dibley') has Parkinson's. He is coming to the Cambridge Junction, 21st May as part of his inspiring country-wide 'Incurable Optimist' tour. More details on [his website](#): or from the [Junction](#).

## RESEARCH

Many will have already seen the two one-hour documentaries recently on BBC TV about the trial of a Parkinson's treatment where a drug was delivered directly to the brain. The programmes are still available on BBC iplayer but access expires soon: <https://www.bbc.co.uk/programmes/m0002tjw>.

Patients in this trial were either given a drug (GDNF), administered via a 'port' created in the side of the head, or a dummy treatment (placebo). The placebo group also had ports inserted. *Both* groups showed improved symptoms but, sadly, there was no significant difference between them overall. So there is no evidence of any effectiveness from the treatment. Scans *did* find some visual evidence of improvements to affected areas of the brain in those given the drug, but no organisation has come forward with funding to support further trials. This is a disappointing outcome but the BBC has done well to devote two moving and scientifically accurate full-length programmes on Parkinson's disease shown at 'prime time'. This will have helped raise public awareness of the condition. Meanwhile over 1000 other Parkinson's research studies have already been published in the medical journals this year. The search for a cure goes on.

**DO GET IN TOUCH:** As Editor, I'm always happy to hear from members with ideas, news items or suggestions for ways in which this newsletter might be improved.

**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:** Secretary, Judy Millward (01763 838742); Treasurer (Donations), 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).