

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Chair's Monthly Newsletter

Happy May,

Well I'm certainly having a "Happy May" as I've just taken 8 amphetamines. I believe this would be admitting to a criminal offence, as they are class B drugs, if it were not for the fact that I'm sitting in Hammersmith Hospital with an arterial line in my left wrist and an intravenous cannular in my right arm. I may have sparked your curiosity as why I am here. The answer will be discussed after the diary dates and basically involves my new fetish with being locked in small, confined spaces.

Dates of the diary

- **Tuesday 28th May**-Shalford Village Hall Social Meeting (2.00pm)
Brook Frances Rose Huxford, postdoc student at St Bartholemews is carrying out a project on biomarkers for Parkinson's. She will talk about her initial research results and provide general information about the role of Parkinson's biomarkers in the diagnosis of the condition.
- **Thursday 6th June**
New weekly day for our new subsidised Seated Yoga Class in Godalming-see leaflet at end of this newsletter for details. Contact Lindsey Brown by email lindseyliveyoga@gmail.com
- **Tuesday 25th June**-Shalford Village Hall Social Meeting (2.00pm)
Dave Pascoe, from Willow Consultancy and Training, will give a presentation on Government Benefits-'Your entitlements and opportunities to make life easier when living with a chronic condition.'
- **Saturday 20th July -Summer Picnic**
Our Summer Picnic at Great Halfpenny Farm,Halfpenny Lane, Guildford. Ticket prices- Adult £5, Child £3, Family ticket-2 adults and up to 3 children £15.
For tickets please apply to Clare Price by email cprice@guildfordparkinsons.org.uk

Other Charities/Good Causes

Our members are often serial philanthropists. While I don't expect to fill the Newsletter with every event in the locality I feel it proper to give these groups/activities a shout-out!

- Pilgrim Morris (Morris Dancers). The Tour List 2024 is available now at www.pilgrimmorris.org.uk. This year they are raising vital funds for Shooting Star Children's Hospices.
- Music in the Park Godalming – The schedule of events around the Bandstand for 2024 is now published – see www.godalmingbandstand.co.uk

Now back to my dabbling with drugs and small spaces! The background is that I am taking part in a clinical trial conducted by the University of Exeter using the facilities of the Imperial Clinical Research Facility and sponsored by the Michael J Fox foundation.

As you know, Parkinson's Disease (PD) is caused by the death of dopamine generating neurons. While numbers vary, consensus is that by the time motor related symptoms (like tremors) become obvious then between 50% to 80% of the neurons are already dead. An individual is typically diagnosed after a DAT scan that shows the amount of dopamine being produced.

If I understand correctly, the hypothesis of the study I have volunteered to participate in is that before the dopamine neurons are killed, a smaller number of serotonin receptors are also killed. This seems even more plausible when one finds serotonin is related to constipation, mood, sleep etc. Effectively the main non motor symptoms of PD. Obviously, if this is proven to be a correct hypothesis then it could lead to identification of those susceptible to eventually being diagnosed with Parkinson's.

So how do you prove it? This study looks for evidence of People with Parkinson's having damage to serotonin systems. I am scanned for 90 minutes with a mildly radioactive die with blood samples taken every 5 minutes. I am then dosed with amphetamines that "stimulate" the serotonin receptors and the whole scanning process repeated. Comparison of the scans will hopefully identify something. If by some miracle an important change in the brain is reflected by blood biomarkers then this might be a gamechanger as it provides the starting point for simple population screening.

Today represents Day 2 of a 4 day trial. I have already done Day 1 and have been scanned for 90 minutes. The study team are exceptional and every care is taken to keep me safe and comfortable including Taxis and hotels. Before anyone rushes forward to join be aware that being laid in a PET scanner for about 4 hours with your head completely immobile and unmedicated is a big ask. Definitely not for the claustrophobic or anyone who cannot make it through the day without caffeine

(banned as it has a mild stimulation of the serotonin receptors and hence would invalidate the baseline).

Coincidentally, I found I am following in the shoes of Keith Black, our Membership Secretary, who had taken part in a previous scanning trial and who returns for regular follow-up scans



Chair Yoga ~ Parkinson's

WHERE

Conservative Club,
Oxborough Room,
2nd Floor (lift),
11 Wharf Street,
Godalming. GU7 1NN

WHEN

6th June to 11th July
Thurs 2.45-3.30pm
6 week block £39

PAYMENT

Miss L Brown
Sort: 070116
Acct: 31681880

lindseyliveyoga@gmail.com

www.liveyogatherapy.com