PARKINSON'SUK CHANGE ATTITUDES. FIND A CURE. JOIN US.

Happy July,

Those of you who are regular readers of this newsletter will know that I am currently taking part in a clinical trial, led by the University of Exeter, using the advanced imaging equipment of the Imperial Clinical Research Facility in Hammersmith Hospital, London and sponsored by the Michael J Fox Foundation in the US.

In June I completed the last of 4 PET scans, had a DaTscan and all that is left this year is a set of MRI tests which unfortunately are delayed due to late commissioning of a brand-new state of the art MRI scanner.

Given that my consultant advised me on diagnosis that a DaTscan would not add value I often wondered why other people were often offered one. Now that I have finally got to have one I thought I'd try to extract some knowledge from my imaging doctor. Accordingly, this month I'm doing serious research and hope to give my simple explanation of what that DaT Scanning is all about. By the end you should be able to answer this teaser... 'If the two differences between Ioflupane 123 and my previous PET scan dyes are 10,000 or 4 then what are the units associated with 10,000 or 4?' [I didn't understand the teaser as written – does this make sense to you/is it what you meant to say??]

Before brains melt, let's see what is available from the Branch and that needs adding to your diaries in the coming months.

• Saturday 20 July - Summer Picnic -1.00 pm- 5.00 pm

- Our Summer Picnic will be held again 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
- We are also running a Raffle for the Summer Picnic, with a fabulous 1st Prize of a 2-night stay at the Glass House, a fabulous AirBnB in the grounds of Great Halfpenny Farm. The 2nd Prize is an equally great experience for someone to be the passenger in a 1946 MG sports car on a drive through Surrey lanes. The 3rd Prize will be a 10 year old bottle of Bushmills Irish whisky. Tickets are priced at £2.00 each and are now on sale through Committee members and lead volunteers.

Shalford Village Hall last Tues of the month social meetings

- There are no SVH meetings at end July or end August,
- The next meeting is 24 September and will feature a demonstration of Chair Yoga.

Members Update

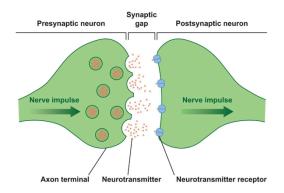
 Dave Pascoe, from Willow Consultancy and Training, gave a presentation at the June Shalford Village Hall social meeting on Government Benefits -'Your entitlements and opportunities to make life easier when living with a chronic condition.'

- It transpired that some of our members have not claimed allowances to which they are clearly eligible.
- Clearly we cannot do this topic justice here and accordingly we will make it a focus for the September edition of *The Park*.
- o In the meantime, to obtain the help from Parkinson's UK (PUK), please phone their helpline 0808 800 0303. Alternatively ring the main switchboard 020 7932 8080 and they will put you through to the helpline. PUK then contacts the local advisor who in turn contacts the member seeking help.

Now back to my DaTscan ...

I should start with a big bold caveat; I am not in any way medically trained in neuroscience or the like. The following is simply what I have picked up through various conversations with consultants or reading around the Internet while waiting for the 4 hours for my DaTscan dye (Ioflupane 123) to circulate. I might have misunderstood and it may be technically mumbo-jumbo. So if you decide to use this information as part of your O-level neuro biology course and you get an F minus then don't come moaning to me:-).

Synaptic Transmission



Before I looked into the topic my understanding was that impulses were transmitted from the brain through the nerves to muscles. While this is basically correct, to understand the next level of detail it is necessary to be more accurate with terminology. The figure to the left shows the typical representation of a synapse as drawn by Dr Joji the doctor who explained this to me.

Some terminology. Nerve cells are called neurons. If these were connected directly to the brain then quickly one would collapse of fatigue as the Central Nervous System was simultaneously bombarded with thousands of inputs. Instead they are connected to Synapses which is what this explanation is all about.

An impulse is transmitted over a synapse, which is a small gap between neurons, through a specific process. When an electrical signal, or impulse, travels along a neuron, it reaches the end of the neuron called the presynaptic terminal. Here, the impulse causes the release of chemicals called neurotransmitters.

These neurotransmitters move across the synaptic cleft, the space between the neurons. They then bind to specific receptors on the next neuron, known as the postsynaptic neuron. This binding process allows the signal to be passed along, continuing the transmission of the impulse.

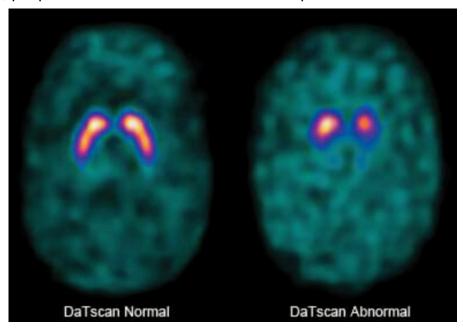
After the neurotransmitters have transmitted the signal, they need to be cleared from the synaptic cleft to prevent continuous stimulation of the postsynaptic neuron. This is done through a process called re-absorption, or reuptake, where the neurotransmitters are taken back into the presynaptic neuron for reuse or broken down by enzymes.

In the case of Parkinson's disease, this process is disrupted. Parkinson's disease affects neurons that produce a neurotransmitter called dopamine, which is crucial for smooth and coordinated muscle movements. In people with Parkinson's disease, the neurons in a specific part of the brain (the substantia nigra) gradually break down and die. This leads to a decrease in dopamine levels, which means that signals are not transmitted as effectively across synapses. As a result, people with Parkinson's disease often experience

symptoms like tremors, stiffness, and difficulty with balance and coordination.

Back to terminology: DaT is a protein used by the Dopamine Transporter in the reuptake back to the presynaptic neuron.

A DaTscan uses a radioactive dye (loflupane 123) which binds to a specific part of the brain and can be detected by single-photon emission computerized tomography



(SPECT). An individual with a normal number of functional dopamine neurons will produce a 'tear drop' image. Those with less functioning neurons will produce an abnormal result.

I understand there is no objective scores for the degree of abnormality and hence all agree it is an adjunct to other diagnostic procedures.

In hindsight I can now appreciate that presenting to my Consultant with multiple Parkinsonian symptoms he must have felt the DaTscan would not change his diagnosis.

So this explains how I filled my 4 hours. Being a curious chap, I asked the obvious question 'why I had to wait 4 hours with DaT but not for my previous 4 scans'. The answer it seems is simple – the Ioflupane 123 was a cheap commercial dye worth £10 while my previous dyes had cost £10,000 each to produce. So that's £40k spent on dye alone. It seems in the world of dyes you get what you pay for \odot