

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

Happy August <<**First Name**>>!

It is with great pleasure that I welcome new members to the Branch. Hopefully these individuals will gain something from the subsidised activities we run or from the social aspects of being part of a community. Most importantly, for the volunteers who make up the committee, we feel a real buzz from doing our bit to ensure that nobody need face Parkinson's alone.

The main advantage of having new members is that I get the chance to remind everyone of the Branch mantra.

So repeat after me "Parkinson's consultants advise it is vital for all People with Parkinson's to "

- Stay physically active
- Stay mentally active
- Stay socially active

The following represent activities and events that align with these elements. My advice, to all, is make your life easy and take part in as many activities and social events you can and in doing so, you will achieve excellent compliance with the mantra :-). Whilst August tends to be a quiet month for Branch events, as many members are away on holidays, please note:

1. The next Recently Diagnosed social evening will be at the Grantley Arms, Womersley on Tuesday 13 August at 7.00pm ([link](#))
2. The next monthly Friendship Group social evening will be on Wednesday 21 August at The White Hart, 19 Bourne Road, Godalming at 7.00pm ([link](#))
3. The next Shalford Village Hall afternoon social meeting will be Tuesday 24 September at 2.00pm when Lindsey Brown will be giving a Chair Based Yoga demonstration. NOTE- there is NO Shalford Village Hall meeting in August ([link](#))

4. The next Parkinson's Voices is on 6 August Emily Bollon, Creative Director of Motivation by Music, is running the current 'term' of Parkinson's Voices at the Busbridge village hall. The classes all start at 11.45 am with Zoom participants asked to sign in slightly earlier to ensure they are set up ([link](#))

I also want to thank Clare and John Price for letting us once more use the gardens of Great Halfpenny Farm for our annual Summer Picnic on 20 July. It proved to be very popular with approx. 100 attending, and it was great to see so many young children enjoying the various games provided. Attendees enjoyed the odd glass (or two) of Pimms, some excellent cakes and tea, and a stocked tombola to gamble away their small change. We ran our first proper Raffle for great prizes. All in all a splendid event... 'Oh, and by the way we made over £1,600 for Branch funds!'

I appreciate by now some of you may be getting worried by my new professional demeanour. Last month's newsletter was a serious explanation of synapses and the start of this newsletter is something that a "normal" Chair would write. No need to worry, I'm still a madman at heart that generally finds the world funny.

I'm not sure of the Parkinson's UK rules on politics but this last month we saw a landslide result bring a Labour Government into power. Those who know me will know I am not particularly political but I have to say I'm leaning towards Labour for the reason described below. I think it is common knowledge that, under the Tories, the NHS struggled with demand and waiting lists soared. There were daily patient reports on the news of folks waiting years to see a Neurology Consultant.

Now just 3 weeks into a Labour Government, all is sorted - as evidenced by the appointment invite letter I received this week.



St George's University Hospitals

NHS Foundation Trust

RJ7 – St George's Hospital

Blackshaw Road

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London

SW17 0QT

Mr David Lowther

www.stgeorges.nhs.uk

Mon to Fri: 08:00 to 17:00 hours

Tel: 020 8725 4321

24 July 2024

Patient Number: [REDACTED]

NHS Number: [REDACTED]

Dear Mr Lowther

This letter is to confirm that a **telephone** appointment within the Neurology Service department has been made for you on:

Tuesday 23 July 2024 at 13:30 hours

As you see it was sent 24 July for an appointment on 13:30 on 23 July. Now you can't fault that for reactivity. All you need is a TARDIS

As with all things, while it did make me chuckle, once you look in greater detail, you soon find there are often mitigating circumstances. Here is the background story behind the above.

As I have discussed on numerous occasions, I have no embarrassment at being diagnosed with Parkinson's. Additionally, there is very little that I would not share as I believe, shining a light on to the condition reduces its power over me.

I have told many of my diagnosis story, and the fact that for me personally, I was so concerned I might have a life limiting condition such as Motor Neuron Disease I felt that Parkinson's was in the "bit of a bummer" category. What I have rarely shared is the elephant in the room - I have young onset Parkinson's, people with YO are the most likely to have a genetic cause, and by extension this leads onto the unanswered question of "Have I passed my condition on to my offspring?"

The elephant remained in the corner of the room, for probably in excess of 10 years until two separate strands of activity woke it from its slumber.

The first was a conversation with my Consultant at which point genetics were mentioned for the first time. Never shy to put myself forward I asked what he could do to help me. He immediately replied that he would be more than happy to refer me to St George's Hospital for a full genome sequencing. So autumn 2023 I was invited to attend a consultation at St Georges Hospital.

In terms of procedure it was technically simple - blood test samples taken to enable the process to start. In terms of process it was far more confusing. For example, I don't understand the selection criteria (I believe you need be a YO individual) and why the process is expected to take between 12 and 18 months. Anyway, I was happy that I had started.

The second parallel activity was the clinical trial I have started and which you can read about in previous newsletters. Here genetic testing is part of the overall "understand your patients" activity. I was explained that for economic purposes the trial would collect a number of patient samples before sending them as a batch.

So the race was on.

Now it transpires my results from St Georges arrived last week and to enable them to be logged a "dummy appointment" need be created. Unfortunately, the NHS App is too clever/dumb that it sent me the invite.

I'm tempted to let you wait till next time to disclose the result but that seems cruel. So the news is the elephant has gone as my results are negative. In other words, my cause is not genetic and hence I cannot pass it on.

I am of course pleased but mindful there are others that receive the opposite answer and need our support.

Have a great month.

Enjoy our latest Newsletter online

<https://www.guildfordparkinsons.org.uk/?p=2824&preview=true>

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