

Merry Christmas!

There are no reminders this month.....only my sincere wish that you all enjoy this Christmas!

I'll admit, sometimes I get bogged down in the details and forget to step back and see if what I'm doing is really hitting the mark. For example, I have a few different choices to make with how I allocate my volunteering time. Should I be writing this newsletter? Should I be answering emails and keeping people informed? Figuring out what I should invest my energy in is tricky and can feel a bit overwhelming. So how do I deal with this efficiently? I've found a solution I like to call 'taxi driver therapy' and I'll tell you all about why I think it's so effective.

While not every taxi driver will play along, many are quite happy to let you sit up front and have a chat. The beauty of it is they typically don't know much about Parkinson's, so they listen with a fresh perspective and a logical mind. And just like a little impromptu therapy session, you'll never have to see them again, which makes it a no-pressure way to talk things through.

I had the opportunity this week. Here is a quick summary -

The conversation started with Jeff (taxi driver) asking, "PD? What is that?" and then we got onto what the symptoms are and what medications people use. This naturally leads to talking about the lack of cures or disease-modifying drugs, and how the mainstay medications, like L-dopa, have been around for decades.

Eventually, the conversation turned to what can one do beyond just medication and social support. I called out the Mantra and considered the conversation complete. Jeff then challenged me with a question along the lines of '...this is clearly the major priority in your life and I hope they find a cure with stem cells and the like soon but in the meantime, what else **can you do** to move all these constraints on. "Wow! What a challenging question – I instinctively knew the answer but somehow had not isolated it well enough - I've realized the missing piece is **supporting research**.

Research is the cornerstone of progress in understanding and treating Parkinson's. Without it nothing will ever improve. Additionally, it can also be a genuinely cathartic experience for those who take part. Many people find that contributing to research gives them a real sense of purpose and a boost from knowing they're helping to push the science forward.

While not everyone is able or comfortable participating in every type of study—some can be quite invasive or demanding—there's often a range of opportunities out there.

That's where the Parkinson's UK "Take Part" section comes in. On their website, you can easily find a hub of different studies and see how to get involved in a way that suits you (<https://www.parkinsons.org.uk/research/take-part-research>). There's a range of opportunities—some less invasive than others—that can offer a real sense of purpose and the boost that comes from helping push the science forward.

I've just been part of "the living lab" experiment. Let me tell you about it.....

How can you help the Parkinson's scientific community by making tea and toast?

A team of the UK Dementia Research Institute at Imperial College London and the University of Surrey are conducting vital research aimed at improving the accuracy of Parkinson's assessment. At present, the tools available, such as the "quacky bird" tests, are rudimentary, which means that analysing disease progression often requires two or more years of monitoring and very large cohorts of participants. This makes clinical trials both expensive and slow. As a result, pharmaceutical companies may be less inclined to invest in Parkinson's research compared to other areas.

However, if reliable assessments could be achieved in as little as three months, it would be transformational. Clinical trials could be run far more quickly and at a lower cost, with fewer participants needed to reach conclusive results. In short, rapid and accurate assessment would revolutionise how Parkinson's trials are conducted and remove some of the key barriers to investment and innovation in this field.

To address the projects aims they face challenges on two fronts:

- Technical - Create and calibrate appropriate sensors/radars to identify small changes in gait and other physiological changes
- Human – People will be people and "Show timing" is when an individual with a variable condition, such as Parkinson's or dementia, temporarily presents as lucid, coherent, and more capable than they usually are in front of medical professionals



How do they propose to address these challenges? On the 9th floor of their campus building in White City, the team have created a standard London apartment. It has everything you would expect including a bed, a kitchen and seating area. Supported by the delightful Emma and Jenna you will be asked to:



- Do some admin
- Complete some paper based cognitive tests
- Make Tea and Toast
- Complete some measurement tests
- Carry out some computer based tests
- Make Tea and Toast again

Details are available in the Patient Information document but in summary;

- Participants are requested to wear dark colours.
- You are allowed to be normally medicated.
- There are no invasive elements – you are simply requested to wear a hat similar to a bicycle helmet, one or more sensor socks and wrist sensors.
- The team will help address your transport needs (I was provided a taxi both ways)
- The whole activity lasts around 5 hours (you get fed and can decline Toast if you want)

If you would also like to discuss taking part then feel free to email the team (ukdri.crt@imperial.ac.uk), who I'm sure will welcome you.

Have a Happy Christmas and I'll see you again in the New Year!

David