

## RESEARCH REPORT, PARKINSON'S, AUGUST 2022

I'm Susan, and as Research Champion for the Barnsley branch of Parkinson's UK my role is to keep you updated with progress towards developing successful treatments. I do not have a medical or scientific background, having been a geography teacher at Wath Comprehensive all my working life. However, I was diagnosed with Parkinson's in 2004 and have had plenty of time to read about my condition.

I also try to encourage you to take part in clinical trials and this summary sheet is representative of the variety of topics that caught my attention.

At present there are 145 clinical trials in the UK:

51 are in phase 1 (initial testing)

66 are in phase 2 (looking at safety)

28 are in phase 3 (large-scale trial of effectiveness)

Recent improvements in stem cell production have enabled researchers to start their first cell transplantation trials, important to those studying repurposed drugs to see if they are effective on other illnesses.

### LARGE CLINICAL TRIALS

#### **GDFN trial** (Glial Cell-Derived Neurotrophic Factors)

Volunteers in the **GDFN trial** had a major operation to insert a stent to enable the drug to reach the correct part of the brain. Researchers were convinced they would be able to demonstrate that the drug was effective and would help to stop, or even reverse, the effects of Parkinson's. However, the final statistics did not support the more optimistic views of the volunteers involved in the trial as well as the researchers. Many of those who volunteered to take part reported a remarkable improvement, but not enough to meet the criteria of success. Even so, convinced that the drug had great potential, the scientists kept pushing for more research. The problem is that the drug must reach the correct part of the brain and requires stents to be inserted because the molecule is large and cannot be injected for delivery by the bloodstream, it has to be delivered directly into the brain.

Parkinson's UK bravely decided to meet the challenge and take responsibility for the trial – Vivify Biotech is the company set up to make the protein needed for use in research. Negotiations with health authorities take time and finding sponsors to fund the £10 – 15 million required will not be easy, nevertheless, prospective trial start date is the end of 2022.

You will be pleased to know that not all clinical trials are always so complex!

#### **TOPHAT PD trial**

**Ondansetron** is a low-cost drug frequently used in the NHS for sickness during chemotherapy. Researchers hope it will be effective in the treatment of hallucinations. A total of 306 volunteers are needed who have been diagnosed with mild or moderate dementia, have a stable drug regime and not taking apomorphine. All the early stages of development have been done. A drug to help with the depressing effects of hallucination would be very important because at present there are few options.

#### **CHIEF PD trial**

Another example of repurposing of drugs is the trial I was on called CHIEF PD. It is for a repurposed drug called a Cholinesterase Inhibitor, presently used for memory loss it could alleviate dyskinesia.

## **PASADENA trial**

There is a new drug that has the potential to slow down, stop or reverse the progression of Parkinson's. The drug is called **prasinezumab** and has been specially developed to target the protein known as *alpha synuclein*. This protein is believed to be responsible for the accumulation of sticky deposits in the brain, affecting the brain's ability to work properly. So far it appears to improve motor functions. It is a phase 2 trial and therefore it is significant that Roche, one of the big pharmaceutical companies, has shown interest in developing the drug.

## **PREDICT PD trial**

This aims to find the earliest symptoms indicating a prelude to developing Parkinson's later. It would enable treatment to start earlier and, potentially, more time symptom free; 10,000 volunteers are needed.

## **TECHNOLOGY TRIALS**

Another group of trials aim to help people with Parkinson's who need ways of coping with the variety of symptoms. They are non-medical but could improve the quality of life. One device which seems promising is a smart phone MMP4D. It keeps a continuous record of an individual's movement symptoms, such as tremor, wearing off, dyskinesia or how a drug regime is working. Consequently, it compiles much more detailed data for a medical practitioner to make informed decisions. If an individual is asked about their symptoms, they only have a snapshot of a short period of time, whereas the device is running all the time.

There are also clinical trials underway looking at the effectiveness of nerve stimulation. There are battery packs that can send electrical impulses through the body to help relax muscles. Another device activates nerves in the leg to help balance and walking.

With the huge number of apps available it is virtually impossible to choose those that would suit you. That is why Parkinson's UK has built an app library for you to download for free.

To see what is available, visit [www.parkinsons.org.uk/devicesandapps](http://www.parkinsons.org.uk/devicesandapps)

## **LIFESTYLE, EXERCISE AND DIET**

The problem in telling people how beneficial it is to exercise regularly is that they find it difficult to get started. You need to work out how you fit that into your daily schedule. It may be that you return to a sport or activity you took part in some time ago, or you may want to try something new. It's often easier to stay motivated if you are in a group and that is why the keep-fit classes the Barnsley branch provides, on Monday afternoons, are so important. A small group of our members set up a Nordic walking group which has helped improve their mobility. Additionally, there are summer walks that are available. What about swimming, an exercise bike, or a walk around a local park? You can even exercise sitting down.

Diet, there appears to be very little information about the best kinds of food that might help with Parkinson's. There is only one thing I have come across and that is a drink made from barley and aims to provide good bacteria for the gut. Given that there is a close link between the brain and the gut it is hoped that this will help the many people who have ongoing stomach problems. The results of the trial have not yet been released.

## **HOW TO VOLUNTEER**

If you are interested in taking part in a trial, there are plenty of opportunities. Some need information that can be collected by questionnaire or by the detailed completion of a questionnaire over the internet. Responding to a questionnaire is a common way of collecting information, especially post-Covid.

Begin with the Parkinson's home page: <https://www.parkinsons.org.uk>

Click on Research

Click on Hub

Fill in your postcode

A list will appear of trials in your area, usually with a closing date.

Most trials have their own criteria, commonly age and the length of time you have been diagnosed.