'Deck the hall with boughs of holly'

PEMRIG
PARKINSON'S EAST MIDLANDS RESEARCH INTEREST GROUP

A happy Christmas to all East Midlands' people with Parkinson's and those further afield, their families, health professionals and others reading this December 2025 edition of the PEMRIG newsletter. Please consult the PEMRIG website (https://pemrig.org.uk) for details of past laboratory visits, research seminars, our 2024 Face 2 Face meeting and our recent lunch-time talks.

PEMRIG is one of thirteen Parkinson's UK affiliated 'Research Interest Groups' around the country. The aim of the RIGs is to interest People with Parkinson's (PwPs), their carers and friends in the exciting Parkinson's research going on in the UK and all round the world. By following the research, it is clear that steady progress is being made to understand and beat Parkinson's.

If you know of anyone who wants to be added to the mailing list for this monthly online newsletter, please ask them to contact Liz Nash, Research Support Network Lead at Parkinson's UK, by email at: lnash@parkinsons.org.uk.

PEMRIG NEWS

1. PEMRIG welcomes Dr Carlo Breda and Mike Wynn to the steering group. Carlo lectures at De Montfort University, Leicester where his team use fruit flies in their Parkinson's research. Mike Wynn has an industrial and financial background. He was treasurer of his village U3A for six years before retiring.

2. VIRTUAL LABORATORY VISIT – *MONDAY, FEBRUARY 9th, 2026, 2.00 to 3.30pm*

Join PEMRIG on a virtual visit to Professor Perdita Barran's laboratory in Manchester where research is in progress to characterise the chemical changes that occur in the sebum of PwP, what causes the changes and how such changes are associated with the seborrheic dermatitis which occurs commonly in PwP. Joy Milne, who is hyperosmic, amazed the Parkinson's community when she first reported years ago that she could detect PwP by their altered 'smell'. Professor Barran's team now use sophisticated chromatography and mass spectrometry methods to identify the sebum changes. A spin-off company, Sebomix, has been set up to develop a rapid non-invasive test for Parkinson's based on the changes occurring in sebum. Such a test should potentially offer a rapid diagnosis of Parkinson's before the onset of symptoms. Professor Barran also co-authored the recent report that certain dog breeds can be trained to detect Parkinson's by the changed composition of their sebum. There should be plenty to discuss at this lab visit.

To join this special lab visit, register here: *https://parkinsons-org-uk.zoom.us/meeting/register/MGsimVtYS3mZW11JCivFBg*

HOT NEWS – EJS ACT-PD, THE WORLD'S LARGEST CLINICAL TRIAL FOR PARKINSON'S, IS RECRUITING IN LONDON AND NEWCASTLE

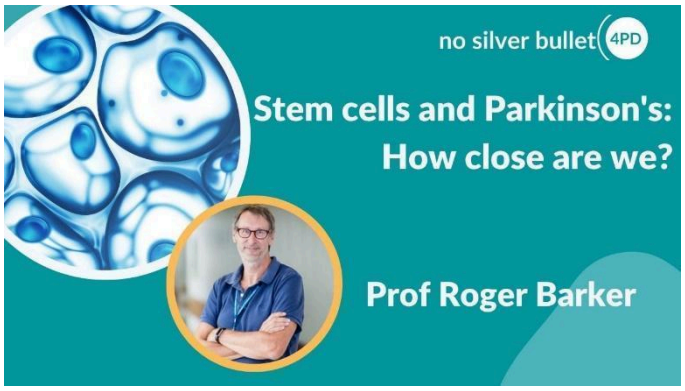
NOW. RECRUITMENT IN 40 OTHER SITES AROUND THE UK WILL OPEN IN 2026.

For more information about ACT-PD see the trials section in this newsletter.

FORTHCOMING AND RECENT TALKS ABOUT PARKINSON'S

1. STEM CELLS AND PARKINSON'S: HOW CLOSE ARE WE?

WHEN: December 8th, 7.30pm



This is the next NSB4PD talk and in this session Professor Roger Barker will review the latest global developments in stem cell research for Parkinson's. He will also address key questions from the audience. This is a great opportunity to hear directly from a leading expert in the field.

The webinar will explore where research truly stands today and how close we might be to seeing real therapeutic benefits.

Roger Barker is Professor of Clinical Neuroscience at the University of Cambridge and Consultant Neurologist at Addenbrooke's Hospital. He is Co Editor in Chief of the Journal of Neurology, and he serves on the Editorial Board of several neurology journals. He is heavily involved in international research collaborations and clinical trials.

To attend this webinar please register at *this link.*

2. WHERE ARE ALL THE PARKINSON'S DRUGS and TRIALS TO THERAPIES - CATCH PEMRIG's ONLINE LUNCH TIME SEMINAR AGAIN!

WHO: DR KEVIN MCFARTHING and DR SIMON STOTT

Use *this link* to listen to the talks again.

3. MEDICAL CANNABIS AND PARKINSON'S: WHAT YOU NEED TO KNOW

In this webinar the NSB4PD community joined PD Buddy for a Q & A session on medical cannabis and Parkinson's. Beatrice from PD Buddy and Curaleaf experts Drs Mark Weatherall and Simon Erridge discussed what's known, what's safe and what's next.

They explored what medical cannabis really means in a clinical setting, including how it differs from recreational use and how cannabinoids like THC and CBD may help manage symptoms like tremor, rigidity, pain, sleep disturbances and mood changes. The discussion also covered access routes, dosing forms, safety considerations and which patient profiles benefit most. They gave plain explanations, practical takeaway tips and an opportunity to ask your own questions.

Catch this webinar again at : **https://www.youtube.com/watch?v=7tMtQX2ZArE**.

The organiser PD Buddy (https://pdbuddy.app/) is a free, comprehensive app for people with Parkinson's and their carers, offering smart symptom tracking, practical daily management tools, educational sites, etc.

4. Parkinson's Walking Glasses: PD Buddy interview with Scott McLeod, Co-Founder of StrydAR – a new recording.

In collaboration with the PD Buddy app, this interview featured Scott McLeod, co-founder of StrydAR, who discussed StrydAR's groundbreaking Parkinson's Walking Glasses. These innovative glasses use visual cueing technology, inspired by fighter-pilot helmets, to help people with Parkinson's overcome mobility challenges such as freezing of gait, slowness, and balance issues.

The interview explored how the holographic cue works, which symptoms it targets, and how quickly users notice improvements in walking, posture, and confidence. Scott also explained when and how to use the glasses, whether prescription lenses are needed, and provided details on cost and trial options.

For anyone living with Parkinson's, or supporting someone who is, this interview offered practical insight into an innovative tool designed to make everyday life safer, easier, and more independent. A 2 min 40 sec feature on Scottish TV provides a helpful introduction to the topic: here.

Listen to this webinar again at: https://www.youtube.com/watch?v=RUCVr6QalYU&t=32s.

5. NEW VIDEO RECORDING UPDATE ABOUT PROGRESS ON THE AMBROXOL TRIAL

To emphasise the ASPro-PD trial in progress I have again included this updated video from Prof Anthony Schapira.

ASPro-PD (Ambroxol to Slow Progression in Parkinson's) is a Phase 3 clinical trial to assess whether Ambroxol, a cough medicine, can slow or stop the progression of Parkinson's motor symptoms.

Full details of the Trial can be found on the Cure Parkinson's website here.

To watch the recording click on this link.

6. PAR-CON 2025

If you *want to catch up with any of the talks at PAR-CON 2025 click on this link.*

PARKINSON'S RESEARCH NEWS

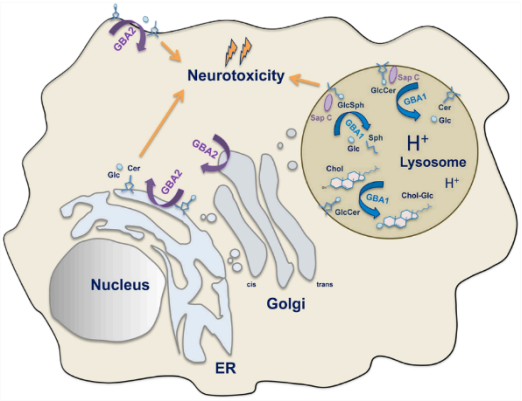
1. Parkinson's research at de Montfort University, Leicester – Professor Dan Sillence's laboratory

Editor writes: On November 12th I was attending an online scientific meeting on 'New Approaches to the Treatment of Parkinson's and noted that one of the poster abstracts was from the laboratory of Professor Dan Sillence at de Montfort University at Leicester. His name sounded familiar as I remembered that I had once taught a student with the same name at York and, on enquiring, it turns out to be the same person. I asked Prof Sillence for a brief summary of his Parkinson's research and what he has written is below. Like Dr Carlo Breda who is also at de Montfort University, Dan Sillence's lab uses fruit flies for the reasons Dr Carlo Breda explained in a past edition of this newsletter.

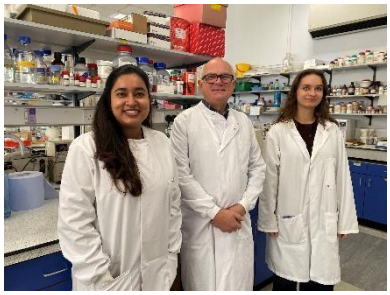
‘Developing a ‘glycolipid statin’ for GBA-linked Parkinson’s disease

Zuzanna Kula, Manavi Perera,Carlo Breda and Dan J Sillence
Leicester School of Pharmacy, De Montfort University

A popular theory for Parkinson's is that the neurotransmitter dopamine isn't packaged correctly and instead oxidizes and this leads to brain cell death. A particular pump on the surface of dopamine vesicles in some nerve cells in the brain increases the acidity of the vesicles and this is necessary for correct dopamine packaging. We have identified a particular pool of glycolipid (a sugar-containing fat) in the endoplasmic reticulum (ER), the cell’s manufacturing centre, that appears to be important in the regulation of this pump. It is known that several mechanisms in cells are not correctly functioning including acidic structures called lysosomes which use the same pump as dopamine packaging.



Lysosomes are waste processing units in every cell in the body and are indispensable for cell survival. Lysosomes process old, worn-out or toxic materials which are broken down into pieces and recycled or destroyed. In Parkinson’s, these structures do not work as they should do. We have been doing some research into diseases related to Parkinson’s and we have discovered that the lysosome’s activity can be affected by a particular sort of glycolipid – not just the quantity but exactly where the sugar-containing fat is located in the cells. We think that, similar to good and bad cholesterol, the same is true for glycolipids. Good glycolipids can reactivate defective lysosomes and have the equivalent effect of a statin that increases the level of good glycolipid by inhibiting its breakdown in the endoplasmic reticulum. By increasing the quantity of this ‘good’ glycolipid in just the right place using a drug which inhibits an enzyme called GBA2, we found that lysosomes were much more active. This resulted in a beneficial effect in the survival of brain cells which can be, in turn, very beneficial in Parkinson’s. Because GBA2 has not been studied in Parkinson’s yet, our project will be the first study investigating the potential of targeting the GBA2 enzyme to treat Parkinson’s in a variety of models. We also wish to study GBA1 which is similar to GBA2 but is normally present in the lysosome. In Parkinson’s, there is a link between mutations in GBA1 and Parkinson’s but it is not known how this works at the brain cell level. We will test a new theory that the altered pH optima that occurs in the mutant GBA1 is making it active outside the lysosome and breaking down glycolipid in the wrong place, leading to problems with the pump and dopamine packaging.



Manavi Perera, Dan Sillence and Zuzanna Kula in their lab.

Editor adds***: The GBA gene provides instructions for the Glucocerebrosidase (GCase) enzyme. Mutations can lead to a loss of enzyme function, causing a buildup of certain fatty glycosphingolipids and impairing the function of lysosomes, the cell's recycling centres.***

2. BEECHBAND

Nothing new to report and no more accounts of user’s experiences from my Parkinson’s nurse. As reported last month a new version of the BeechBand, the 100D model, with quieter motor and strap without a buckle has been available from November 10th for £54.50. I am still waiting for a model with longer battery life to appear before investing again to do more testing. The link to the BeechBand site is ***here.***

3. Parkinson’s UK – RESEARCH ROUNDUP

The latest edition of Parkinson’s UK’s Research Roundup email was sent on 28 November. It contained links to some exciting new projects PUK are funding, as well as the latest research news and opportunities to get involved. You can sign up to receive future Research Roundup emails online here.

Most important, in the Editor's opinion (as he has slept badly the last few nights), is the online research conference on **SLEEP ISSUES AND PARKINSON's** being promoted by the Parkinson's Southeast Research Interest Group SERIG. Sleep and nighttime problems are common in Parkinson's and can happen at any stage of the condition. This meeting will give you a chance to hear from leading experts about the latest research into sleep and Parkinson's.

WHEN: SATURDAY, December 6th 10.30-1.00pm
WHERE: Online via zoom

Register for SERIG's meeting at this link.

4. CURE INSIGHT – Cure Parkinson's Biannual Research Roundup

Cure Parkinson's is putting money into proposals to treat Parkinson's by what are known as 'combination therapies' and have recently put out a £2 million research call for proposals to test combination therapies to slow or stop progression of the problem. This idea stems from the fact that several mechanisms are affected in Parkinson's, e.g. mitochondria, fail to produce enough energy, waste disposal pathways don't function properly, and pro-inflammatory pathways are increased. A combination therapy is a treatment that involves two or more active agents to achieve the desired effect. These drugs may target separate pathways linked to the condition, or one may be used to enhance the effectiveness of the other.

Visit the Cure Parkinson's website to learn more: https://cureparkinsons.org.uk/

PARKINSON'S TRIALS NEEDING VOLUNTEERS

(Don't forget that by volunteering for many of these opportunities you are consenting to your email being shared with the researcher(s) involved in the project).

1. Edmond J Safra Accelerating Clinical Trials in Parkinson's (EJS ACT-PD), the world's largest clinical trial for Parkinson's, is now recruiting in the London and Newcastle areas. By mid-2026 all 40 sites across the UK should be open for recruiting. Cure Parkinson's and Parkinson's UK are both involved in funding this new multi arm multi stage (MAMS) platform in which several drugs are tested against one placebo compound and where a drug that is observed to be ineffective can be withdrawn and replaced by a new drug.

Visit this webpage to learn more and to see the recruiting sites across the UK: https://www.parkinsons.org.uk/research/edmond-j-safra-accelerating-clinical-trials-parkinsons-ejs-act-pd

Overall, the trial will need 1600 volunteers and is costing something like £29 million. The Parkinson's UK link above sets out the requirements and **includes a form to register your interest** even though most local centres haven't started recruiting yet. This is a great chance to get involved in a new big trial. The first two repurposed drugs being tested are terazosin and telmisartan both being in the final Phase 3 stage of testing. A third compound, ursodeoxycholic acid will be added in 2026.

2. WHAT DO YOU THINK ABOUT BRAIN STIMULATION THERAPIES?

Researchers at the University of Nottingham want to understand how people with Parkinson's view using brain stimulation therapies. These therapies include Deep Brain Stimulation (DBS), focused ultrasound, nerve stimulation and more. Your opinions will help researchers develop non-drug approaches to treating Parkinson's.

Who is needed: 1000 people with Parkinson's

What is involved? Completing a 10-to-20-minute online survey in which you will be asked about your Parkinson's symptoms and your thoughts on different brain stimulation therapies.

For more information, please read **the participant information sheet.**

If you need support completing the survey, please contact the researchers by email by email at caitlin.smith1@nottingham.ac.uk or isabel.farr1@nottingham.ac.uk.

The deadline for taking part in this research is 1 March 2026.

3. SUPPORTING DECISION MAKING IN PARKINSON'S

Hannah Kisley, a PhD student at University College London, wants to improve how PwP, their partners and family members are supported when they need to make difficult decisions about future care and support.

Hannah needs to work with PwP to make sure her research reflects their experiences and focuses on what matters most to them.

Who is needed: People with Parkinson's and their carers.

What is involved: You will join an advisory group which will ensure that the project is relevant, inclusive and deals with what matters most to people living with Parkinson's and those who support them.

You can get involved from home in a way that suits you by email, phone, or by joining an online group meeting. Hannah will offer support to help you join a video call. You will be offered payment for your time**. Read our guidance on payments on our website.**

If you've got any questions, or if there are ways Hannah can support you to get involved, contact her via email at **hannah.kisley.23@ucl.ac.uk** or by phone on **02039 872 372**.

4. DOES EXERCISE BUILD RESILIENCE IN PEOPLE WITH PARKINSON'S?

A PhD student wants to understand how exercise affects the resilience of people with Parkinson's. The student is keen to learn how exercise may help PwP feel stronger and how it can improve their quality of life. This research will also explore what type of exercise people with Parkinson's prefer. This trial is based at the Medical School in Derby Royal Hospital so is very convenient for PwP in the Derby area.

Who is needed: ***16 people with Parkinson's who are over 40 years old, can walk 30m with or without a walking aid and can travel to Derby Medical School. Sorry but anyone with a diagnosis of dementia or any other neurological conditions is ineligible.***

Where: ***The study is based at the Medical School in Derby Royal Hospital so is very convenient for PwP in the Derby area.***

What is involved:

- ***Travel to Derby Royal for two study visits, the first involving an hour's screening for the study***
- ***The second visit will last 3.5 hour including breaks and you will complete assessments of your strength, balance and flexibility,***
- ***On this second visit you will take part in cycling or walking at a moderate pace for 40 minutes.***

You will be paid £150 for travel expenses and for taking part in the study. Parking spaces will be provided for anyone coming by car and members of the research team will provide help with Turkish, Arabic, Portuguese and Mandarin if needed. A supporter may attend the study visits if necessary.

For more information read **the participant information sheet.**

To take part email Mehmet at: Mehmet.cagatay.yildirim@nottingham.ac.uk or sign up here.

5. A PLACEBO-CONTROLLED CROSS-OVER TRIAL OF RHYTHMIC 10HZ MEDIAN NERVE STIMULATION FOR THE REDUCTION OF PARKINSON'S TREMOR.

Who is needed: 60 volunteers with a diagnosis of Parkinson's and a resting tremor in one or both hands/arms.
Where: Department of Psychology, University of Nottingham.

How: The trial involves 3-4 visits to determine how an active stimulation compares to a placebo stimulation. You will be randomly allocated into the active or placebo groups but volunteers in the placebo group will be able to try the active stimulation at the end of the trial.

During the first visit researchers will deliver questionnaires to assess your symptoms, tremor and wellbeing. To assess your tremor, a short video will be taken of you and researchers will also give you an accelerometer device to take home for the duration of the trial. This measures your tremor frequency. At the second visit, you will repeat the questionnaires from the first visit and then receive one session of active or placebo stimulation. On your third visit, you will repeat the questionnaires given at the first and second visits. If you are in the placebo group, you will have the opportunity to try the active stimulation during this third visit and be invited back for an additional session. You will also be asked to perform a simple movement task once during your first and last visit and twice during visits where you receive stimulation. The task involves tapping on circles on a screen as fast as you can.

We will offer an inconvenience allowance of £10 per hour, and we will contribute up to £45 per visit to help you with travel expenses for your visit to the University of Nottingham.

For further information about this work please contact: mairi.houlgreave1@nottingham.ac.uk or caitlin.smith1@nottingham.ac.uk. There is no closing date for recruitment, but we will stop recruiting once we have 60 eligible participants.

Editor adds: Mairi says they still need more volunteers……!

6. EXPERIENCES OF PEOPLE WITH PARKINSON'S USING MENTAL HEALTH SERVICES.

This trial is open until April 2026. Learn more about what is required by using this link.

7.THE CAN-PDP TRIAL – IS CANABIDIOL AN EFFECTIVE TREATMENT FOR PARKINSON'S PYCHOSES?

About 60% of PwP experience hallucinations - seeing/hearing/feeling things that are not really there. Many also suffer delusions (ie. strange beliefs). Collectively these are known as Parkinson's psychoses (PDP). The CANnabidiol for Parkinson's Disease Psychosis trial is a clinical drug trial investigating whether cannabidiol (or CBD) is a safe and tolerable treatment for reducing these psychotic symptoms in PwP. This trial is still open for recruitment in multiple sites across England.

This study is important because the current treatment strategies for PDP are either not very effective, safe, or convenient for everyday use. So, we are looking at cannabidiol (or CBD) as a safer, more tolerable alternative treatment. More information can be obtained via *this link.*

8. UNDERSTANDING EMOTION MANAGEMENT AND WELL BEING.

Click here for more information.

9. The LITE study: Improving our understanding of Parkinson's.

Researchers at the University of Dundee want to find new ways to diagnose Parkinson's as it progresses. They also want to understand if there are different types of Parkinson's which could help predict how people respond to new treatments. The study will explore why some people with a genetic risk of developing Parkinson's develop the condition and why others with the same risk don't.

To find out more, please visit: https://www.parkinsons.org.uk/research/lite-study-improving-our-understanding-parkinsons

CURE PARKINSON'S/PARKINSON'S UK JOINT 'GET INVOLVED IN RESEARCH' LEAFLET.
Cure Parkinson's and Parkinson's UK have put together a co-branded leaflet with a number of ongoing opportunities to get involved in research for people with Parkinson's in the UK - click here to access the leaflet.

PARKINSON'S UK RESEARCH SUPPORT NETWORK. This site advertises other trials needing volunteers. So click on the Take Part Hub on the Parkinson's UK website to find other research projects needing volunteers.

Newsletter comments, ***queries, corrections, arguments, and submissions to the Editor (Martin Rumsby) at: martin69747@gmail.com. If you have any top tips for coping with your Parkinson's, special diets, exercise regimes, etc., that you would like to share with us in this Newsletter, email the editor.***

Any mistakes in the details above are entirely the fault of the Editor!

Thanks: ***The Editor greatly appreciates help from Mia from the PEMRIG steering group with help in proofreading this newsletter and with shortening long links.***