

PEMRIG

PARKINSON'S EAST MIDLAND RESEARCH INTEREST GROUP

NEWSLETTER

AUGUST 2026

Unforeseen circumstances prevented the PEMRIG steering group meeting to agree to become PMRIG now covering both the East and the West Midlands. This change will be ratified at the next available opportunity.

The larger PM-RIG will still be one of thirteen Parkinson's UK affiliated 'Research Interest Groups' around the UK and our aim, as always, is to interest PwP across the Midlands in the exciting Parkinson's research going on all round the world and in doing so, raise the hopes of all PwP that progress to slow, stop, and even reverse Parkinson's is being made.

If you know of anyone who would like to receive this monthly newsletter, please ask them to email Liz Nash, Research Support Network Lead and acting PEMRIG chair at: lnash@parkinson's.org.uk. This newsletter is now being circulated as word and pdf documents since the Editor has heard of an instance where the word version would not open on an Apple Mac but the pdf version does. Thanks to Peter of the Ripley group for the information.

From the Editor – What's on offer?

Sign up for the Midlands Research Event (tickets are limited) and the online Sillence/Breda lab visit both described below. The nutrition-based webinars on July 30th and September 8th should have some good tips. Listen to Prof Shapira summarise their exciting findings in the PD biome study and read the discussion in the research section. Join trials to design an app to help with impulsive behaviour and with DBS.

1. PEMRIG NEWS

i. MIDLANDS RESEARCH EVENT – organised by Parkinson's UK and PEMRIG.

When: WEDNESDAY, SEPTEMBER 9th, 2026, 9.30am – 3.00pm

Where: TRENT CONFERENCE CENTRE – Unit 1, Easter Park, Lenton Lane, Nottingham NG7 2PX. Trent Conference Centre is a fully accessible auditorium.



Are you interested in the latest advancements in Parkinson's research? Whether you are a dedicated researcher, someone affected by Parkinson's, or simply curious about new discoveries shaping the future of Parkinson's care, this event is for you! It brings together researchers and experts from across the Midlands to provide exciting research updates, alongside interactive taster activities demonstrating the importance of staying active.

Speakers

Professor David Dexter is the Director of Research at Parkinson's UK, where he oversees the charity's grant funding, biotech programmes, and research communications. He is a prominent neuropharmacologist who helped pioneer the Parkinson's UK Brain Bank in 2002.

Christine Huston is a Specialist Physiotherapist and Therapy Team Leader for the Parkinson's Disease Multidisciplinary Team (MDT) at Nottingham University Hospitals (NUH) NHS Trust. Christine specialises in movement disorders, physical rehabilitation, and therapy support for Parkinson's patients and leads weekly Parkinson's Warrior classes, an advanced exercise programme that incorporates both physical and cognitive activity for people living with Parkinson's.

Dr Qadeer Arshad is an Associate Professor and neuroscientist in the School of Psychology and Vision Sciences at the University of Leicester. He specialises in clinical neuro-otology, focusing on balance disorders, vertigo, space and motion sickness, and neurological rehabilitation, particularly for patients with Parkinson's. He will be speaking about *"Improving balance through physical activity and brain training"*.

Professor Stephen Jackson is a Professor of Cognitive Neuroscience at the University of Nottingham. His research centres on using multimodal brain imaging and wearable non-invasive brain stimulation technologies to treat movement and neuropsychiatric disorders such as Tourette syndrome and Parkinson's. He will be speaking about *'Investigating a Wrist Worn Device to help control tremor'*.

This research event will give you the opportunity to find out more about community support offers, to network with peers, share ideas and gain fresh insights in an accessible and welcoming environment.

The event is free and includes lunch and refreshments. The event is limited to 70 so book your place today by [completing the booking form on Eventbrite](#) or, if you require support with booking, email us on adm.midlands@parkinsons.org.uk.

Travel Support: Parkinson's UK is committed to making this event inclusive for everyone. If travel costs are a barrier to your attendance, please inquire about our available travel bursary support during registration.

ii. VIRTUAL RESEARCH LAB VISIT, 3.00 - 5.00pm SEPTEMBER 30th. Join PEMRIG to hear about Parkinson's research being led by Professor Dan Sillence and Dr Carlo Breda at De Montfort University, Leicester. Dan and Carlo use fruit flies in their research. They summarise their work in the research section further on. Register for this lab visit: [here](#).

2. FORTHCOMING AND RECENT TALKS ABOUT PARKINSON'S

a. 'HOW NUTRITION AND SIMPLE KITCHEN STRATEGIES CAN TRANSFORM SYMPTOM MANAGEMENT FOR PwP'.



When: September 8th, 2026 at 17.00 (London).

In this webinar interview, co-authors Dr. Michael Okun and Emily Truscott discuss their upcoming book, 'The Parkinson's Plate: A Health and Diet Guide to Manage Your Journey'.

Moving away from dense science and restrictive rules, the authors describe how they blend medical expertise with straightforward nutrition strategies tailored for real kitchens. The discussion covers essential topics such as gut health, medication interactions, and simple, high-calorie recipes designed to respect the daily energy and time of people living with Parkinson's and their carers. Register for this talk at the new Parkinson's Insights website (see section 3 below for link) or [here](#).

b. THE MIND DIET MASTERCLASS: SCIENCE-BACKED BENEFITS FOR BRAIN HEALTH AND PARKINSON'S

When: Thursday, July 30th, 7:00 pm - 8:30 pm GMT+1



Join us for **Food is Medicine for Parkinson's (Part 7): The MIND Diet Masterclass**. Here we will explore the powerful connection between nutrition, brain protection, and physical mobility. In this session, we will break down the science of the Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet, highlighting specific, evidence-based foods that help slow cognitive decline and support motor function. Whether you are living with

Parkinson's, caring for a loved one, or looking to optimize your neurological health, you will hear about practical, daily dietary strategies designed to protect your brain and keep you moving well.

Dr. Puja Agarwal is a trained nutritionist and a nutritional epidemiologist at the RUSH Alzheimer's Disease Centre and an Assistant Professor of Internal Medicine at RUSH University Medical Centre.

Register for this talk via Parkinson's Insights or [here](#).

c. 'The PD Biome Study and the Gut Microbiome' - a PD Frontline/RAPSODI research team webinar

In this webinar held on July 20 Professor Tony Schapira discussed their latest exciting research on 'Exploring the relationship between the gut microbiome and Parkinson's disease.', Milly Anderson introduced the PD Biome study, which over 300 members of their RAPSODI cohort have participated in, and Georgie Pittwood discussed how Sharing PD Frontline's future communication plans and how Ambassador feedback is helping to shape their approach'. Listen to this webinar [here](#).

Editor adds: Read a discussion of this work in the research section 4 below.

d. WHAT BLOOD, URINE, HAIR AND STOOL CAN REVEAL ABOUT PARKINSON'S



Dr Mischley explored in depth the insights that can be uncovered through comprehensive laboratory testing of samples of blood, urine, hair and stool from PwP compared with non-Parkinson's controls. She focussed on actionable insights-how you can interpret lab findings to make targeted lifestyle adjustments such as nutritional changes, to manage your condition.

You can catch this talk again on the 'Parkinson's Insights' website accessed at the start of Section 3 below

The editor adds: This talk gave some interesting insights but here in the UK, my consultant has never mentioned me having my hair, urine, blood or even my faeces examined to give clues about how my Parkinson's is progressing. With the findings that the microbiome of PwP differs from non-PwP controls, maybe such routine analyses of the gut microbiome would be a good idea so the floral composition of the microbiome can be adjusted back to match the microbiome of non-Parkinson's controls.. But what is an analysis of my hair going to reveal?

3. PARKINSON'S RESEARCH NEWS

a, PARKINSON'S INSIGHTS



The NoSilverBullet4PD and PD Buddy teams have joined forces to launch Parkinson's Insights, a collaborative platform created by PD Buddy and NoSilverBullet4PD. Their mission is to move you beyond the search for a "silver bullet" empowering you with the latest research and practical tools. This new website brings everything together in one place to help you stay informed and proactive.

Access Parkinson's Insights at [this link](#).

b, SEPTEMBER 30th LABORATORY VISIT 3.00pm – 5.00pm

Editor: Dan and Carlo have provided summaries of their research. These are inevitably rather technical, so I have included a lay interpretation of some key words below.

Dan writes: Parkinson's (PD) has no disease-modifying therapies, with current treatments addressing symptoms rather than the underlying neurodegeneration. A key unmet need is restoration of **lysosomal** function, which is impaired across multiple PD subtypes and leads to toxic accumulation in neurons.

We have identified a novel, first-in-class approved and clinically safe drug targeting the lysosomal enzyme **GBA2** (IC₅₀ ~20 nM) also known as GCase. Our preliminary data in **Drosophila** GBA-PD models demonstrate complete rescue of motor function and lifespan, supporting strong translational potential. Mechanistically, GBA2 inhibition increases cytosolic glucosylceramide ("beneficial glycolipid"), which restores lysosomal acidification and function. This enhances cellular clearance pathways and reduces neurotoxicity.

Importantly, this mechanism may also improve dopamine handling. Increased **cytosolic-facing** glucosylceramide appears to support proton pump activity required for both lysosomal acidification and dopamine vesicle loading. This dual effect addresses two central features of PD pathology: lysosomal dysfunction and impaired dopamine packaging, which contributes to neuronal toxicity.

Our hypothesis is that GBA2 inhibition restores lysosomal and dopaminergic vesicle function, reducing neurodegeneration across PD subtypes. Treatment in **Gaucher's disease** targets glucosylceramide synthesis (IC50 ~40 uM) and is considered very safe with only occasional mild side effects. This project is highly translational, repurposing an existing drug to accelerate clinical application. If successful, it will establish GBA2 inhibition as a broadly applicable therapeutic strategy and enable rapid progression toward clinical trials in PD patients.

Carlo writes: In Parkinson's signs of neurodegeneration begin long before dopaminergic nerve cells actually die. One process that contributes to early neurodegeneration is a failure in intracellular trafficking pathways that transport proteins, lipids, and other substances between organelles and which is crucial for maintaining cellular homeostasis and signal transduction. **Rab GTPases** are protein master regulators of intracellular trafficking acting as cell "post carriers", and growing evidence points towards their central role in neurodegenerative diseases including Parkinson's. Among them, **RAB39B** has recently emerged as a gene of major interest, mutations causing intellectual disability and an aggressive early-onset form of Parkinson's associated with Lewy body pathology. Despite this strong clinical link, the cellular function of RAB39B remains largely unexplored.

Our research has revealed that **fruit flies (*Drosophila melanogaster*)** that lack dRab39, the fly **ortholog** of RAB39B, display Parkinson's and intellectual disability associated "symptoms".

These findings establish dRab39 as a powerful new model to explore how defects in cellular trafficking are linked to neurodevelopmental disorders, including intellectual disability and autism, and with neurodegeneration in Parkinson's disease. Our work suggests that disruptions in cell "logistics" may represent a common mechanism underlying both altered brain development and the progressive neuronal degeneration seen in Parkinson's. Our work opens up new avenues for therapeutic intervention.

Lysosomes – tiny organelles full of hydrolytic enzymes in cells which work in an acidic environment to degrade and recycle damaged cell components like misfolded proteins, eg alpha-synuclein. Dysfunction of the endolysosomal system is implicated in the pathogenesis of both sporadic and familial Parkinson's.

GBA2 – glucocerebrosidase-2, variant of an enzyme involved in sphingolipid metabolism and cell membrane stability. The most common genetic risk factor for PD are variants in the **GBA** gene.

Drosophila – fruit fly - Carlo explained in depth why fruit flies are such a valuable research tool in a previous PEMRIG newsletter.

Cytosolic facing – all membranes in a cell have a bilayer structure of amphipathic complex lipids. One half of every membrane round an organelle or round the whole cell will face the intracellular liquid cytoplasm, the other half is oriented externally.

IC50 - the concentration of an inhibitor eg a drug that is required to bring about 50% inhibition of a measurable effect.

Gaucher's disease - a genetic disorder in which glucocerebroside accumulates in cells and certain organs. The disorder is a hereditary deficiency of the enzyme glucocerebrosidase.

RabGTPases – a large family of molecular switch proteins which become active when they exchange bound GDP for GTP inside cells and they switch themselves off as their intrinsic GTPase activity hydrolyses the bound GTP back to **GDP**- amazing. Rab GTPases regulate many steps in membrane trafficking, including vesicle formation, vesicle movement along actin and tubulin networks, and membrane fusion.

RAB 39B – gene coding for Rab39B, a protein member of the RABGTPase gene family involved in vesicular trafficking in cells.

Ortholog - homologous genes that are the result of a speciation event.

c, Research Commentary

The PD Front Line group have very recently published the results of a study investigating if the bacterial content of the gut microbiome is influenced by mutations in the **GBA1(glucocerebrosidase-1)** gene, a risk factor for Parkinson's, and by Parkinson's severity.

The paper is entitled '**Microbiome signature of Parkinson's Disease in healthy and genetically at-risk individuals**'.

It can be accessed at <https://doi.org/10.1038/s41591-026-04318-5>

Using a new approach, the PDbiome team analysed the bacterial content of stool samples from 271 people with Parkinson's, 43 people with a mutation in the GBA1 gene and 150 healthy controls. The results show that the bacterial composition of the gut in PwP is distinctly different from normal people without the condition and that gut bacterial changes are detected most consistently in people with the most severe Parkinson's symptoms whether they were GBA1 positive or not. Importantly, the bacterial

content of healthy (non-PD) PwP with the GBA1 gene was more like those with Parkinson's suggesting that analysis of gut bacteria may be used to identify an individual's risk of developing Parkinson's, enabling early support.

4. PARKINSON'S RESEARCH TRIALS NEEDING VOLUNTEERS

i. IMPOWER: an app to help with impulsive behaviours in Parkinson's

Ellen Poliakoff and Erin Beeston at the University of Manchester are developing an app to help people with Parkinson's manage impulse control behaviours. The app will involve training with pictures. The researchers would like to invite people affected by Parkinson's to complete a survey about the app to ensure this reflects their needs and experiences. This feedback will help the team develop the application's content and design.

What?	Complete a short online survey to share your thoughts. It is anticipated that the survey will take around 15 minutes.
When?	By Monday 31 August
Where?	Online at this link: https://www.qualtrics.manchester.ac.uk/jfe/form/SV_1S6SQhNWjRG8hsq
Who?	People with Parkinson's, and People who support people with Parkinson's

For more information email Erin at: IMPOWERParkinsons@manchester.ac.uk

ii, Complete a survey to develop an app for DBS assessments.

Researchers Mark Humphries and Caitlin Cook at The University of Nottingham are working with a Medtech company called [Machine Medicine Ltd](#) to develop an app. The app aims to better identify those who may benefit from [Deep Brain Stimulation \(DBS\)](#). It's hoped it will also improve information sharing and collaborative decision-making between clinicians and people with Parkinson's during the pre-assessments for DBS. They would like to hear from people affected by Parkinson's to help shape the app and ensure it meets their needs.

What is involved: Complete a survey by August 12th. This may take you 15 - 30 minutes to complete.

Who: People with Parkinson's and their carers.

Where: Online survey [here](#)

Alternatively you can complete the survey on a Word Document which you can obtain by emailing Laura at researchinvolvement@parkinsons.org.uk to send on to Caitlin.

iii, 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 email the following: Mairi.Houlgreave1@nottingham.ac.uk or caitlin.smith1@nottingham.ac.uk.

Editor: There is no closing date for recruitment, but more participants are still needed to reach the necessary total of 60.

iv, TOP HAT - TRIAL OF A LICENSED DRUG AS A PARKINSON'S HALLUCINATION TREATMENT

Research teams across the UK are investigating if ondansetron has a meaningful treatment effect on Parkinson's and Lewy Body Dementia hallucinations. As this is an already licensed low-cost drug, if the research shows significant outcomes, ondansetron could be available for people with Parkinson's who experience hallucinations within the next few years.

Who is needed: 306 people diagnosed with Parkinson's or Lewy Body Dementia (LBD) who:

- experience visual hallucinations, see things that aren't there, at least once every week.
- are not taking apomorphine or any anti-psychotic medication.
- and have been taking a stable dose of Parkinson's or LBD medication for 28 days before starting the research.

Where; At Sherwood Forest Hospitals NHS Foundation Trust, **Kings Mill Hospital**, Sutton In Ashfield, NG17 4JL, near Mansfield. (Plus a number of other sites around the UK)

What's involved? If you are eligible to take part, you will either receive ondansetron or dummy medication tablets for 12 weeks, which will be shipped to you via a courier. The research team will maintain regular contact throughout to take assessments and let you know how much medication to take. This contact will be through telephone, video call, and face-to-face. 3 face-to-face visits are required and, for some research sites, home visits may be an option.

For more information: contact the TOP HAT team at o.zubko@ucl.ac.uk or call 02031089073 and leave a voicemail message. More information is also available on the Parkinson's UK website: [here](#).

Hear about Maria and Desmond's experience of taking part in the TOP HAT trial
"I'd really encourage anyone thinking about it to take part. It was so easy, just one more pill. Read more about Maria and Desmond's experience in the trial online [here](#).

Parkinson's Research (JPR@Research+Me) is a UK-wide online registry that makes it easier for people with Parkinson's to get involved in research. What does it do? A secure sign-up process will collect information from interested people with Parkinson's, so that they can be matched with relevant studies and receive regular newsletters about new trials and research opportunities

Details of trials supported by Parkinson's UK and Cure Parkinson's are given in the links below for you to consult if interested. Don't forget that by volunteering you may be consenting to your email being shared with the researcher(s) involved in the project.

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.

Sign up using this link to receive the CURE PARKINSON'S Research News: <https://cureparkinsons.org.uk/newsletter/>.

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 of the PEMRIG steering group with help in proofreading this newsletter and with shortening long links.

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