

PM-RIG

PARKINSON'S MIDLANDS RESEARCH INTEREST GROUP

SEPTEMBER NEWSLETTER

PEMRIG has now morphed into PM-RIG, dedicated to spreading the word about Parkinson's research across the whole Midlands area. As PM-RIG we hope to attract bigger audiences to our varied online and face to face research and welfare seminars, visits to Parkinson's Research Labs to get the very latest research results and advice on living well with Parkinson's. We also hope that expansion will result in more volunteers joining the steering committee to help us run events. We urgently need a stronger female perspective on the steering committee either as a carer or lady with Parkinson's. The original PEMRIG logo is used above as we await the updated PM-RIG version.

The thirteen RIGS around the UK aim to interest PwP in the exciting Parkinson's research going on all round the world. In doing so we hope to raise your hopes that a new treatment to slow, stop or even reverse progression is getting closer to becoming available in the clinic.

To receive this newsletter, please email Liz Nash, Research Support Network Lead and acting PM-RIG chair at: lnash@parkinson's.org.uk. The newsletter is distributed as Word and pdf formats.

At a glance – action!

Make a note of PAR-CON26 in Birmingham, sign up for the Midlands Research Event on September 9th (places are limited). PwP under Dr Skelly or Dr Jackson should register for the newly diagnosed/advanced Parkinson's half day information meeting on September 22nd. Sign up to attend PUK's AGM below. Learn about how fruit flies are used in Parkinson's research by registering for the Sillence/Breda lab visit on September 30th. Sign the Neuro Alliance open letter. Sign up for volunteering possibilities that appeal.

Call for a neuro plan now

If you haven't already done so already, [sign the open letter to the Secretary of State for Health and Social Care today](#) and join The Neuro Alliance in calling for a national neuro plan now. Anyone in the UK can add their signature and show their support.

1. PM-RIG RELATED EVENTS

1.1. PARKINSON'S UK ANNUAL MEMBERS ONLINE MEETING



Parkinson's UK
Annual Members'
Meeting 2026

Thursday 1 October

4:45pm – 6pm

When: October 1st, 4.45pm – 6.00pm

You are warmly invited to join us online at this year's Annual Members' Meeting (formerly called the AGM).

This meeting is your opportunity to share your questions and thoughts directly with members of our board of trustees and executive leadership team.

[Click here to read the formal notice and agenda.](#)

Register for online attendance [here](#)

To help us address what matters most to you, we encourage you to submit your questions ahead of the meeting by emailing governance@parkinsons.org.uk or by calling 0800 138 6593. We will respond to every question received, either during the meeting or afterwards in writing. There'll also be an opportunity to ask questions on the day.

1.2. PARKINSON'S RESEARCH LAB VISIT,

When: SEPTEMBER 30th, 3.00 - 5.00pm,

Join PM-RIG members on a virtual visit to hear from Professor Dan Sillence and Dr Carlo Breda at De Montfort University, Leicester about their Parkinson's research. You will learn how fruit flies are used for medical research. Lots of time for questions.

To attend this lab visit you must register: [here](#).

1.3. INFORMATION MEETING FOR THE NEWLY DIAGNOSED OR FOR THOSE FACING ADVANCED PARKINSON'S.

PwPs under Dr Skelly or Dr Jackson at Royal Derby are invited to attend the appropriate morning or afternoon sessions of this meeting

When: Tuesday, September 22nd: Newly diagnosed: 9.30am to 12.00 midday, Advanced: 1.00 pm to 5.00pm.

Where: The Wilmot Community Centre, 16 Wilmot street, Heanor, DE75 7EF.

Contact Shauna Bissett (mob 07805764741) for information on ticket availability.

1.4. MIDLANDS PARKINSON'S UK RESEARCH MEETING

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.



Speakers

Professor David Dexter, Director of Research at Parkinson's UK

Christine Huston - Specialist Physiotherapist and Therapy Team Leader for the Parkinson's Disease Multidisciplinary Team (MDT) at Nottingham University Hospitals (NUH) NHS Trust.

Dr Qadeer Arshad, University of Leicester - "Improving balance through physical activity and brain training".

Professor Stephen Jackson, University of Nottingham - 'Investigating a Wrist Worn Device to help control tremor'. (Editor notes-this is a totally different device from the currently available BeechBand).

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 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.

2. FORTHCOMING AND RECENT TALKS ABOUT PARKINSON'S

2.1. PAR-CON 2026

When: Friday 13 and Saturday 14 November 2026

Where: Online, and at The Vox Conference Venue, Resorts World, Marston Green, Birmingham B40 1PU (limited spaces).

Par-Con is your Parkinson's community convention about living well with Parkinson's. Planned in collaboration with a team of people living with and connected to the condition, Par-Con gives you the chance to learn from researchers, healthcare professionals and the wider community. Hear directly from trusted experts who can explain the latest research and opportunities, guide you through a new diagnosis or changes in your symptoms, and provide interactive sessions with tips to help manage your condition. Sign - up Fee to support the running of the event for in- person tickets Day 1 £15.00, Day 2 £10.00.

2.2, 'Power failure in the Brain - the mitochondrial basis of Parkinson's Disease'. The Edinburgh Parkinson's Lecture online.

WHEN: Tuesday, September 22nd, 7.00 – 8.45pm

The 2026 Edinburgh Parkinson's Lecturer is Prof Miratul Muqit. He is the inaugural Director of the UK Dementia Research Institute/Parkinson's Research Centre, based at the University of Edinburgh. His research group is world-renowned for making fundamental discoveries of how mutations in two genes – PINK1 and PRKN – lead to the accumulation of damaged mitochondria in brain cells. This has contributed to the development of targeted therapies designed to remove damaged mitochondria which have entered Phase 1 clinical trials for Parkinson's patients.

To reserve a place to listen to this lecture live online register: [here](#)

2.3. 'Parkinson's and dementia'

When: Wednesday, September 9th, 5PM BST

In this Cure Parkinson's webinar Prof Tilo Kunath will be joined by an expert panel to discuss the two types of dementia most closely associated with Parkinson's, namely Parkinson's disease dementia (PDD) and Dementia with Lewy bodies (DLB). The panel will discuss what these conditions are, how they compare and the current research climate.



It is estimated that roughly half of people with Parkinson's will experience cognitive changes, the way we think and process information, to some extent; some of these individuals, however, may go on to develop dementia. Parkinson's belongs to a family of conditions called alpha-synucleinopathies, which are characterised by the build-up of abnormal copies of the protein alpha-synuclein. These copies clump together to form Lewy bodies, which disrupt how well cells can function. Although in Parkinson's this primarily impacts neurons in the part of the brain controlling movement, other areas of the brain may also be affected, leading to problems with thinking and memory.

Register for this webinar [here](#)

2.4. '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 will 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 will 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](#).

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



Food is Medicine for Parkinson's (Part 7): The MIND Diet Masterclass.

The speaker explores the powerful connection between nutrition, brain protection, and physical mobility. The science of the Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet is described 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. The talk ends with a valuable question session.

Editor: If you missed this useful talk catch it via Parkinson's Insights at: <https://www.parkinson's insights.com>

3. PARKINSON'S RESEARCH NEWS

3.1. 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](#).

3.2. ONLINE LABORATORY VISIT

WHEN - SEPTEMBER 30th, 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.

3.3. Research Commentary

Partly relevant to the lab visit above the latest **PARKINSON'S NEWS TODAY (AUGUST 26th)** highlights a new study below showing there are fewer friendly gut bugs in patients carrying the GBA1 mutation.

The paper '*Pathogenic GBA1 Variants and their Interaction with the Gut–Microbiota–Brain Axis in Parkinson's Disease*' can be found at <https://doi.org/10.1002/mds.70496>

In summary

- Parkinson's patients with GBA1 gene mutations tended to have distinct shifts in the gut microbiome, with fewer protective microbes and more inflammation-promoting bacteria.
- Mutation carriers exhibit reduced anti-inflammatory butyrate-producing bacteria alongside elevated levels of microbes linked to gut inflammation.
- Further validation studies are needed to better understand the gut-microbiota-brain axis and its impact on Parkinson's progression
- While the overall diversity of gut bacteria remained similar between both groups, researchers uncovered key differences in specific bacterial strains that could influence how the disease progresses.

"This study suggests a subtle shift toward a more pro-inflammatory gut microbial profile in [Parkinson's patients carrying *GBA1* mutations], characterized by fewer butyrate-producing and more pro-inflammatory bacteria," researchers noted.

3.4. HOPEFUL FINDINGS from the STEM-PD trial demonstrates that the approach is safe and may have positive effects on Parkinson's symptoms.

STEM-PD is an early-phase clinical trial which aimed to evaluate the safety and tolerability of a cell replacement therapy for Parkinson's. The motor symptoms of Parkinson's are primarily driven by the loss of dopamine-producing nerve cells (neurons) in the brain; therefore, researchers have proposed using cell transplantation as a potential treatment option for replacing these lost dopamine cells. STEM-PD is testing this approach by surgically transplanting healthy young dopamine neurons into the brains of eight people with Parkinson's. The transplanted neurons were grown from stem cells – special cells which can develop into many different types of cells or tissues in the body. Overall, the treatment was found to be safe and well tolerated by participants. Additionally, six participants reported an improvement in Parkinson's symptoms and were able to lower their medication dosage. It is important to note that this is a very small, open-label trial, meaning all participants knew they were receiving the treatment. Therefore, these findings will need to be validated in a larger clinical trial.

Read the results at: Human embryonic stem cell-derived dopaminergic cells for Parkinson's disease: a phase 1/2 open-label trial. *Nat Med* (2026). <https://doi.org/10.1038/s41591-026-04525-0>

Dr Simon Stott, Director of Research at Cure Parkinson's comments: 'After years of encouraging preclinical research, it is very exciting to see cell transplantation for Parkinson's moving forward in clinical testing. And STEM-

PD are not the only research team in this space. There are groups around the world clinically testing their transplantation approaches, and thus far the results have been reassuring. We look forward to further developments in this space.'

4. PARKINSON'S RESEARCH TRIALS NEEDING VOLUNTEERS

4.1, SUPPORTING THOSE NEWLY DIAGNOSED WITH EXERCISE

Jonathan Gilby, a researcher at Plymouth University, is running a trial to find out if coaching that encourages physical activity helps people newly diagnosed with Parkinson's to get and stay active.

He is looking for 2 people to join his existing Project Advisory Group. The group will make sure the trial is focused on the needs of people with Parkinson's.

What is involved? Join a Project Advisory Group and share your thoughts on The study design, study documents and dissemination plans

When: 3 meetings a year from Autumn 2026 until August 2028. Each meeting will last up to 1.5 hours

Where: Online, via video call

Who: People with Parkinson's and carers, particularly those in the first 5 years of their Parkinson's diagnosis.

To get involved?

Please email Jonathan at jonathan.gilby@plymouth.ac.uk by September 9th (copying in researchinvolvement@parkinsons.org.uk) if you'd be interested in getting involved. Please include in your email: your connection to Parkinson's, including when you or the person you support was diagnosed, a couple of sentences explaining why you're interested in getting involved and If there are any adjustments we can make to help you get involved. If more interest than we have spaces for arises we'll use the information shared in the expression of interest to try to ensure as diverse a range of perspectives as possible.

4.2., 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. k

For further information about this work please email the following: Mairi.Houlgreave1@nottingham.ac.uk

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

4.3.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 PM-RIG steering group with help in proofreading this newsletter and with shortening long links.

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