

PMRIG

PARKINSON'S MIDLANDS RESEARCH INTEREST GROUP NOVEMBER NEWSLETTER

PMRIG is one of thirteen research interest groups (RIGs) around the UK. The RIGs are supported by Parkinson's UK and have a common aim, namely, to make PwP and their carers aware of the latest research and welfare discoveries about Parkinson's going on in the UK and all round the world. In making PwP aware of some of the latest research we hope to raise your spirits that treatments to slow, stop or reverse Parkinson's progression are getting closer to becoming available in the clinic.

Now covering the whole Midlands, the PMRIG Steering Committee hopes to attract more volunteers to join the steering committee to help run events. We especially need a stronger female perspective on the steering committee. Please contact Liz Nash, our acting chair at lnash@parkinson's.org.uk for more information and to add names to receive this monthly newsletter which is distributed as Word and pdf formats. Note that any views expressed in this newsletter are entirely those of the editor or whoever is writing. You should always discuss changes to your medication with your health-care professional.

IN THIS ISSUE

- Sign up to attend PAR-CON26 in person or online,
- Register for the PMRIG seminar on Parkinson's and Motivation on October 26th,
- Sign up for webinars of interest and/or catch up on any missed sessions,
- Shout hurrah for European approval of Hopledo known as Crexont in the USA)
- Read a review of a book entitled Pilates and Parkinson's
- Be one of 1600– register your interest in [joining](#) the EJS-ACT-PD trial

1. PMRIG EVENTS

1.1. 'HOW DO WE STUDY MOTIVATION IN PARKINSON'S?'

PMRIG hosts an online research event with time for questions and answers. Join us to hear about the Parkinson's research of Assistant Professor Romy Frömer and PhD student Thaleia Mouratidou at the University of Birmingham.

When: Monday 26 October 2026, 12 - 1pm

Where: Online via Zoom

Interested in attending? Register via [our Zoom registration page](#).

SUMMARY: *Motivation is crucial to people's health, wellbeing, and success. Thus, understanding its underpinnings is key to improving individual and societal life. An extreme lack of motivation is common in many conditions, including Parkinson's. It can negatively impact people's lives. In our lab, we study motivation and its impairments using gamified tasks as well as recordings of quickly changing brain activity using EEG. In our presentation, we will show you how we do the*

research in our EEG lab and we will tell you what we already know about motivation and the brain processes supporting it. We are currently studying why motivation is impaired in people with Parkinson's. We will be pleased to answer your questions about motivation and hear about your experiences.

2. FORTHCOMING AND RECENT PAST TALKS ABOUT PARKINSON'S.

2.1. PERSONALISING NUTRITION FOR PARKINSON'S



WHEN: FRIDAY DECEMBER 4th at 19.00 (London)

WHERE: ONLINE

Register to attend: [here](#)

In this 10th Part of the 'Food as a Medicine for Parkinson's' series Dr Tanya Denne moves beyond general dos and don'ts. Rather than asking which foods are universally good or bad, this webinar focuses on a far more crucial question: how do you tailor nutrition to your unique body, daily life, and specific experience with Parkinson's? Because no two people experience the condition in the same way, a one-size-fits-all diet simply does not exist.

To bring these principles to life, the speaker will examine three distinct real-world clinical situations, 1, someone struggling with unintended weight loss and muscle depletion, 2, someone managing persistent constipation alongside low appetite and fatigue, and 3, someone navigating frustrating on and off medication fluctuations despite eating an otherwise impeccable diet. Dr Denne will illustrate why offering identical dietary advice across all three would completely miss the mark, highlighting why nutritional strategies must directly reflect individual needs.

For more details about the content of this talk and to hear it go to [Parkinson's Insights](#) and click on this webinar.

2.2. PARKINSON'S FOOD MYTHS - WHAT SHOULD WE ACTUALLY EAT?



WHEN: MONDAY, NOVEMBER 16th at 19.00 (London)

WHERE: ONLINE

Register to attend : [here](#)

Join Dr Tanya Denne for Part 9 in our Food as Medicine for Parkinson's series. In a world saturated with conflicting headlines, wellness trends, and online advice, deciding what to put on your plate can quickly feel overwhelming. This talk will clear through the noise, replace anxiety with clarity, and separate genuine clinical evidence from popular online trends. It will offer a refreshing, evidence-led look at practical nutrition, giving you the facts and confidence to make informed choices that best support your daily wellbeing.

For more details about the content of this talk go to [Parkinson's Insights](#) and click on this webinar

2.3. 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.

2.4. TUNING THE BRAIN'S MOVEMENT CIRCUITS WITHOUT SURGERY



When: Monday, 9 November 2026, 2.00pm (London Time / GMT). Note that this webinar is scheduled to accommodate the speakers' time zones.

In this NSB 4PD Dr Brad Treeby and Dr Tabish Saifee from the company NeuroHarmonics, explore an exciting new approach to influencing brain activity without surgery.

Focused ultrasound uses sound waves to target specific areas of the brain. Unlike approaches that destroy tissue, the technology being developed by NeuroHarmonics aims to modulate brain circuits in a non-ablative, reversible and repeatable way.

The initial focus is on essential tremor, but could this approach eventually have applications in other movement disorders, including Parkinson's disease? Join us as we explore the science behind this technology, what research has shown so far, and what it might mean for the future of treating movement disorders. Michel will lead the interview, with an opportunity for you to put your questions directly to our speakers during the live Q&A.

We will hear how focused ultrasound works, and how sound waves influence activity deep within the brain, what it means for a treatment to be non-ablative, reversible and repeatable, why essential tremor is their initial focus, and what limitations of existing treatments the researchers are hoping to address, what is known about the safety and effectiveness of this approach, could the same principles eventually be applied to Parkinson's and other movement disorders and when might patients benefit?

Register for this talk: [here](#)

2.5. 'DEEP BRAIN STIMULATION FOR DYSKINESIA AND MOTOR FLUCTUATIONS: PATIENT SELECTION, TIMING AND GENDER DISPARITIES'

WHEN: Wednesday 4th NOVEMBER 13.30-15.30. **WHERE:** Online by zoom.

To attend register: [here](#)

This event will bring together three speakers with clinical expertise and lived experience to explore the role of Deep Brain Stimulation (DBS) in Parkinson's, with a particular focus on motor fluctuations, dyskinesia, patient selection, timing and gender disparities. The event is designed to give attendees a balanced view of DBS by combining clinical knowledge with first-hand experience, while creating opportunities for discussion and questions throughout. It aims to improve understanding of DBS and factors that may influence treatment decisions for people with Parkinson's.

Professor Antonella Macerollo, Consultant Neurologist at The Walton Centre and Associate Professor at the University of Liverpool - '*Beyond the On-Off Cycle: DBS for Motor Fluctuations and Dyskinesia*' –

Jo Tosh, Retired Nurse and Principal Lecturer living with Parkinson's and DBS - '*DBS and me: 4 years on*' –

Richelle Flanagan, a Dietitian living with young onset Parkinson's.

If you have any questions about this online event, please email Liz Nash at Parkinson's UK on lnash@parkinsons.org.uk.

2.5. NEUROTROPHIC FACTORS IN PARKINSON'S. - CURE PARKINSON'S AUTUMN RESEARCH UPDATE MEETING.

When: Monday 19 October 1.30pm – 6.00pm.

This hybrid research event focused on neurotrophic factors, a group of proteins that promote the growth, survival, and development of nerve cells. In recent years, researchers have been interested in whether treatment with neurotrophic factors could slow Parkinson's progression.

A recording of this event will be available in the next issue.

2.6. CHANGING THE GUT TO CHANGE PARKINSON'S: FAECAL MICROBIOTA TRANSPLANTATION (FMT).



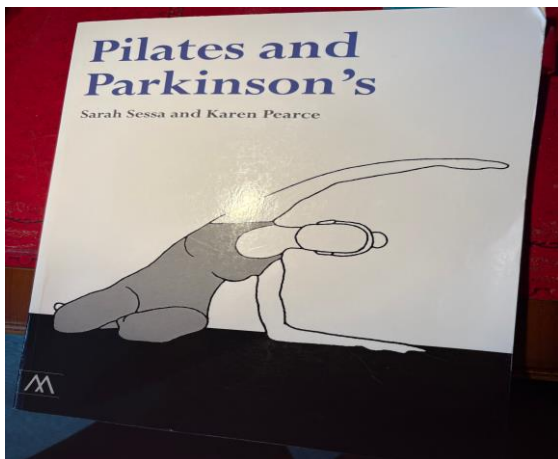
WHEN: October 19th, 2026

The gut is an increasingly important topic of Parkinson's research because there is a complex relationship between the gut, the brain and the immune system. Results indicate that the microbiota of PwP differs from non-Parkinson's controls with more virulent species being present. Changes in the gut microbiome may contribute to Parkinson's and the way Parkinson's develops. Faecal Microbiota transplantation (FMT), the transfer of gut bacteria from a healthy donor to another person is an

approach being studied to repair the microbiome of PwP. In this webinar the speaker discussed what we currently know about the gut-brain axis in Parkinson's, what research into FMT is revealing, what clinical trials of FMT in Parkinson's have shown and how FMT might work. Dr Bruggeman is a movement disorders neurologist at Ghent University hospital, Belgium.

Editor adds: *This was a very well presented and clear talk which is well worth listening to. Their results confirm that the microbiome of PwP is distinctly different from that of normal controls ; there is a reduction in bacteria which produce short chain fatty acids regardless of diet while bacteria which attack the mucus lining of the gut increases. Such changes result in a gut wall which is more permeable. The talk answered my question of how faecal transplants in standardised doses are delivered to the gut.*

Catch the recording: [here](#)



3. PILATES AND PARKINSON'S – Book review

This book was published by Muswellhillpress.co.uk in 2016. It is 156 pages in length, and it was written by **Sarah Sessa**, a physiotherapist and Pilates Instructor, and **Karen Pearce**, a professional ballet dancer, who then trained as a Pilates Instructor. This book is available from Amazon, but the price is prohibitive at £86.00. It is written in simple language with plenty of line drawings and is aimed at Pilates Instructors and those with Parkinson's Disease who have taken up Pilates, rather than the general public. It has some 100 figures, most of which are photos of Pilates elements. It emphasizes the importance of posture, breathing, and coordination.

Editor: Thanks to David of the MPRIG steering committee

for these comments.

3. PARKINSON'S RESEARCH NOTES

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. HOPLEDO (Crexont in the USA) is approved **across Europe and the UK**

The European Commission has officially approved Hopledo, an extended-release oral capsule designed to provide smoother, longer lasting symptom control for people with Parkinson's experiencing motor fluctuations. Combining fast acting granules with slow releasing beads inside a single capsule, the treatment flattens out the sudden peaks and troughs of standard tablets to maintain consistent levels in the bloodstream. In phase three clinical trials, participants taking Hopledo achieved significantly more good movement time each day while reducing their pill burden from around five standard doses down to an average of three. Following this European approval, the treatment is rolling out across European markets, while providing a clear path for fast tracked UK review and eventual NHS evaluation. in October 2026.

The active ingredients are levodopa and carbidopa, and it works by combining immediate-release granules with extended-release beads in a single capsule to provide rapid relief and a longer duration of effect. The benefits are increased daily "on" time (periods when symptoms are well controlled), reduced "off" time, and a lowering of the required daily dosing frequency. A phased rollout across European markets is scheduled starting October 2026.

Editor writes: Beatrice Zatorska kindly allowed me to reproduce her paragraph on Hopledo from the October PD Buddy Buzz site. As someone whose life is governed by bells marking pill time I will be looking into discussing Hopledo with my Consultant when I see him on November 10th. Reducing the number of pills will make planning meals significantly easier.

4. PARKINSON'S RESEARCH TRIALS NEEDING VOLUNTEERS

4.1. 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
Editor: There is no closing date for recruitment, but more participants are still needed to reach the necessary total of 60.

4.2.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](#).*

4.3. CAN-PDP: CANNABIDOL (CBD) FOR PEOPLE WITH PARKINSON'S WHO EXPERIENCE HALLUCINATIONS OR DELUSIONS.

Who is needed:120 people with Parkinson's who are over 40 years old, have experienced any hallucinations or delusions for at least one month, are not taking clozapine, and have someone who can attend study visits with them.

Research teams across the UK are investigating whether CBD is an effective treatment for hallucinations and delusions. If you are interested in taking part or would like more information, please visit the Take Part Hub at 07936545178

4.4. UNDERSTANDING BRAIN CHANGES IN PEOPLE WITH PARKINSON'S

Who is needed: 100 people with Parkinson's aged between 50 and 80 years old, who have had Parkinson's for less than 10 years and can have an MRI scan.

Researchers want to measure the proteins that build up in the brains of people with Parkinson's. This knowledge could help develop more accurate and targeted treatments for people with Parkinson's in the future. This research is led by University College London.

Taking part involves attending up to 5 visits to the research centre in London. If you are interested in taking part or would like more information, please visit the Take Part Hub at www.parkinsons.org.uk/research/brain-changes

Contact the Research Team by email at n.hannaway@ucl.ac.uk or by phone 0203108918

4.5. THE EDMOND J SAFRA - ACT - PD CLINICAL TRIAL.

The Edmond J. Safra Accelerating Clinical Trials for Parkinson's Disease (EJS ACT-PD) platform will transform the way Parkinson's clinical trials are conducted in the UK. As a multi-arm, multi-stage (MAMS) trial platform, EJS ACT-PD will evaluate several potentially disease-modifying treatments in parallel against a shared placebo (dummy drug) group, accelerating the search for effective treatments by testing more drugs faster and more efficiently than ever before.

Interested in getting involved? Complete the registration of interest form at <https://redcap.link/actpd4>

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 MP-RIG steering group for help in proofreading this newsletter and with shortening long links.

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