PEMRIG

PARKINSON'S EAST MIDLANDS RESEARCH INTEREST GROUP

Newsletter – November 2024

Hello to all East Midlands' people with Parkinson's (PwPs), carers, families, health professionals and others reading this November 2024 edition of the PEMRIG newsletter. Please consult the PEMRIG website (https://pemrig.org.uk) for details of past laboratory visits and research seminars.

PEMRIG is one of thirteen Parkinson's UK affiliated 'Research Interest Groups' around the UK. The aim of the RIGs is to interest PwPs and their carers in the exciting Parkinson's research going on in the UK and all round the world. By following the research, we can see the progress being made to understand and conquer Parkinson's.

STOP PRESS!

1. If your Parkinson's gives you trouble swallowing and you have had medication problems on being hospitalised, then please read the first 'volunteers wanted' item where Consultant Dr Robert Skelly and Parkinson's nurse Lisa Brown at Derby Royal Hospital want to hear about your experiences for the 'Levodopa trial' they are planning.

*2. **Professor Stephen Jackson and his team at the University of Nottingham are researching wrist-worn devices to reduce tremor in Parkinson's.** As part of their PPI activities, they need to hear about the everyday lived experiences of people with Parkinson's. The information will help them help them co-create their research. They are interested in understanding the range of motor and non-motor symptoms experienced, the treatments you are receiving and the perceived efficacy of such treatments. They would also value your opinion on potential neuromodulation approaches (brief summaries are provided on each of the relevant techniques). Click on this link to access the survey.*

Please note all data given in the survey is completely anonymised.

PEMRIG EVENTS that you may have missed:

Visit to Dr Charmaine Lang's Parkinson's research lab in Oxford.

Earlier in the year PEMRIG visited Dr Charmaine Lang's laboratory in Oxford to hear about her Parkinson's research and how this is automated to speed up getting results. Here is a link to hear the visit: recording link.

13th RESEARCH and LIVING WELL WITH PARKINSONS Face-2-Face meeting

PEMRIG organised a very successful Face-2-Face meeting in September. The speakers, the titles of their talks and a direct link to their slides or hand-outs are listed below and are also available on the PEMRIG website (see above). Presentations were not recorded but summary notes of the main points from each presentation can be accessed at this link. The speakers were:

Dr Lynne Barker, Associate Professor in Cognitive Neuroscience, Shefield Hallam University: ‘***The gut microbiome and gut-brain axis in Parkinson's: what have we learned so far and possible ways to enhance wellbeing’.*** Lynne’s slides can be accessed here.

Dr Bhanu Ramaswamy OBE (Independent Physiotherapist) ‘***Strength training and brain health’.*** Bhanu’s slides can be accessed here.

Chris Stanley (Retired PE teacher and British Nordic Walking Instructor) -***We are Undefeatable: Living Well with Parkinson’s through Exercise’.***
Sara Jane McCracken (Parkinson's Specialist Nurse and British Nordic Walking Instructor) – ‘***Results of a Nordic Walking survey into the impact, accessibility and diversity of Nordic Walking in People with Parkinson’s***’. Their slides can be accessed here.

Dr Simon Stott, Director of Research at Cure Parkinson's: ‘***An Update on Parkinson’s Research in 2024 and beyond’.*** Simon’s slides can be accessed here.

Helen Scarr (Hatha Yoga & Meditation Instructor): ‘**Seated yoga, breathwork and meditation session’.** Helen’s slides can be accessed here.

PAR-CON 2024 and the Parkinson’s UK AGM? If you were unable to go to this 2 day meeting in Leeds you can listen to the very informative main talks again by clicking here.

WHAT’S NEXT FROM PEMRIG? The PEMRIG Steering group (Chair: John Turner) is meeting soon to plan its programme of research seminars, lab visits, etc., for 2025/26. If you have suggestions for events that PEMRIG could organise or topics you would like to hear discussed, please contact John Turner by email at: **pemrig.uk@gmail.com.**

November 11th – Several PEMRIG members attended an online seminar given by the Pharmaceutical Company Merck Sharp and Dohme (London). We learned about MSD’s research into Parkinson’s and other neurological conditions and there were demonstrations of the instruments necessary for the high throughput screening of potential drugs.

Saturday 23 November. 10.00am to 4.00pm at the Petwood Hotal, Woodhall Spa, LN0 6QG. This event is run in partnership with Lincolnshire Community Health Service Parkinson’s Team and will include talks from healthcare professionals, an opportunity for discussions around key topics such as transport and local support, and Physical Activity taster sessions. There will also be a marketplace of stalls from local providers open throughout the day. Refreshments and lunch will be provided free of charge and there is free on site parking including Blue Badge parking. Any questions, please contact Eleanor Halford, ehalford@parkinsons.org.uk.

Registration is now open via Eventbrite at : Lincolnshire Parkinson's Information Day

Recent and Forthcoming talks about Parkinson’s.

1. The Gut Microbiome and Gut-Brain Axis in Parkinson’s

Dr **Filip Scheperjans** gave a talk on this most interesting subject in the most recent No Silver Bullet 4PD series on September 16th. His talk about ‘***The importance of the gut-brain axis in Parkinson's".*** You can access his talk and the subsequent long and detailed questions and answer session on Youtube: https://www.youtube.com/channel/UCN2A0vGOY6j13Ed1rV64gPQ

Dr Scheperjans investigates the relationship between gastrointestinal symptoms and the microbiome in Parkinson’s, exploring novel treatment strategies. His work includes advanced therapies like drug infusions and deep-brain stimulation, His work is supported by major organisations such as the Academy of Finland and the Michael J. Fox Foundation. He was the first to describe gut microbiota changes in neurodegenerative diseases.

Recent No Silver Bullet 4PD talks.

1, Mucuna Pruriens and the future of Parkinson's care in low-income countries.

This talk was on October 14th by Dr Roberto Cilia MD. Dr Cilia is a leading specialist in the use of mucuna pruriens (MP) a bean which is rich in levodopa. The speaker's main interest is in using MP to treat Parkinson's patients in countries where levodopa is either not available or is not affordable. This is an opportunity to learn about this important legume! Dr. Cilia is a renowned movement disorder specialist based in Milan, Italy. With extensive experience in neurology, he has dedicated his career to improving the lives of patients suffering from Parkinson's disease and other movement disorders.

Editor's comments: MP is a legume found in the tropical and sub-tropical areas of the world. Many legumes eg broad beans contain some levodopa but MP is exceptional in that 6 – 9% of its weight is levodopa. So, it is no wonder that it is taken by some PwP as a complementary medicine to reduce their Parkinson's symptoms. In addition to Parkinson's MP has been investigated for its anti-diabetic, anti-microbial, anti-oxidant, anti-epileptic, and anti-depressant properties, to name a few. Most PwP will be taking levodopa usually in combination with carbidopa which inhibits an enzyme in the blood which degrades levodopa so preserving levodopa's actions for longer. Read more about MP and its use in Parkinson's **here.**

NB. If you are considering taking MP you should first discuss this with your Consultant and you should listen to Dr Cilia's YouTube talk!

2, 'Rebranding Parkinson's - a new patient-centred, evidence-based approach'.

This No Silver Bullet 4PD talk by **Dr Laurie Mischley** will be delivered on November 11th at 7.30pm GMT. The speaker takes the view that ***'It's time to reframe our thinking and take a new approach'.***

Dr Mischley writes: Despite 200+ years of effort, we do not have a system to predict, prevent, halt, or reverse Parkinson's. I will explore the notion that the problem lies in the lens through which we've been viewing PD, the approaches we've been taking, and the assumptions we've been making. This revised patient-centred, evidence-based pragmatic paradigm will include education, symptom tracking, goal setting, counselling, laboratory tests to screen for nutritional deficiencies, counselling regarding diet, daily physical activity, social health, and strategies to encourage financial stability.

Dr Mischley studied naturopathic medicine and epidemiology before embarking on a PhD in nutritional sciences at the University of Washington. Her work is focused on identifying the nutritional requirements unique to individuals with Parkinson's and she has published on coenzyme Q10, lithium, NAD+, and glutathione deficiency (lauriemischley.com). She is Principal Investigator of the Modifiable Variables in Parkinsonism (MVP) Study which attempts to describe why some people with Parkinson's progress slower than others. She is working on ways to study, package and deliver evidence-based lifestyle modification as a therapeutic strategy. She founded the Parkinson Center for Pragmatic Research (parkinson-cpr.com) and the canine scent-based PD screening tool, ParK-9 (Park-9.com), developed a patient-reported outcome measure to assess PD severity (PD-symptoms.com), built the Parkinson Symptom Tracking (PRO-PD) App, and is instructor of the online series, Parkinson School (Parkinson School). Dr. Mischley maintains a small clinical practice at Seattle Integrative Medicine focused on nutrition and neurological health of patients with Parkinsonism.

This No Silver bullet 4PD talk will be over by the time you get this November newsletter but you can access her talk and the questions here.

Mental Wellbeing for People with Parkinson's: A Team Approach'

Saturday, November 23rd 10.30am - 1.15pm

SERIG, the Southeast Research Interest Group are holding an online Autumn Research Conference with the title above. The speakers with the titles of their talks are:
Emma Edwards, Parkinson's Specialist Nurse: '***Parkinson's and how to optimise our mental health'***
Dr Ian Cuthbert, Clinical Psychologist: '***Anxiety and Parkinson's - Causes and Effects'***
Dr Emma Travers-Hill, Specialist in Brief Psychological Interventions, and Delyse Hammet, Counsellor: '***Counselling, Emotional Support and Self-Help Strategies'***

Contact Liz Nash, Research Support Network Lead, on lnash@parkinsons.org.uk or 0207 963 9398 for more information about this meeting or register for the event here.

PARKINSON'S RESEARCH NEWS

Good news - another cell therapy treatment for Parkinson's gives positive results in a twenty-four-month Phase 1 trial.

For the last two years BlueRock Therapeutics, a subsidiary of the German pharmaceutical company Bayer AG, have been running a Phase 1 clinical trial in the USA. The **exPDite** trial aims to evaluate the safety of replacing dopamine neurones lost in Parkinson's with stem cell-derived dopamine-producing neurones. Positive results were reported recently at a Parkinson's Disease and Movement Disorders Congress held in the USA. The stem cell-derived neurone treatment known as Bemdaneprocel was tolerated with no adverse effects. The transplanted cells continued to survive after initial immune suppression had been stopped at 12 months. Improvement in motor symptoms were noted particularly on the group of patients receiving a higher dose of cells.

The results suggest that bemdaneprocel treatment may provide sustained benefits for movement impairments in Parkinson's disease. Motor changes were assessed by standard methods ie The Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Parts II and III which evaluate motor experiences of daily living and motor examination, respectively. In the high dose cohort, the 24-month measurement of the effects of bemdaneprocel on motor symptoms using MDS-UPDRS Part III measured in the "OFF"-medication state, showed a mean reduction of 21.9 points compared with baseline. The low dose cohort showed a mean decrease of 8.3 points.

BlueRock's Chief Development and Medical Officer said "We are very excited to share the 24-month data from the exPDite trial, which shows that bemdaneprocel could be a potentially meaningful treatment option for individuals living with Parkinson's disease. The completion of this study marks an important milestone for bemdaneprocel and sets the stage for the next phase of clinical development. You can read more about this work at this link.

2, Disappointing news. I remember from my laboratory days that research seemed to progress with the tempo of a quickstep which if I remember aright from watching Strictly goes 'slow, slow, quick, quick, slow.' And some preliminary results announced specially for the 194 participants taking part in the 96-week Phase 3 Exenatide-PD3 trial in the UK seem to have hit the disappointing 'fast to slow' stage or possibly even worse, a 'slow to stop' phase. This trial was set up to confirm and extend results of an earlier Phase 2 trial with fewer participants which had suggested that those who received Exenatide showed a slight improvement in movement assessed while off their regular Parkinson's medication and this difference between the two groups was still there 12 weeks after treatment had been stopped. The new Phase 3 trial aimed to show whether there were changes in a participant's motor symptoms throughout the duration of the trial. The main results indicate that there was no significant difference in the progression of motor symptoms between the treatment and placebo groups. When the full results are published an understanding of why Exenatide has not worked as expected should become clearer.

This disappointing result doesn't mean that Exenatide and two other GLP-1 agonists Lixisenatide and Liraglutide in use to treat Type 2 diabetes are no longer of interest in relation to Parkinson's. Far from it! GLP-1 receptors are found in the brain, and experiments in laboratories have suggested that activating these receptors can improve energy production, switch on cell survival signals and many more events. Both Lixisenatide and Liraglutide have been in Phase 2 clinical trials for Parkinsons to see if they can slow or stop the progression of motor and non-motor symptoms. Professor David dexter, who leads research at Parkinson's UK said, 'A longer trial could be a logical next step.' There is a webinar on the Exenatide story at this link: https://cureparkinsons.org.uk/webinar-exenatide-and-parkinsons/.

PARKINSON’S TRIALS NEEDING VOLUNTEERS

1. The levodopa study. Consultant physician Dr Robert Skelly and Parkinson’s Nurse Lisa Brown at Derby Royal Hospital seek information for their LEVODOPA STUDY on how you have coped if you have swallowing problems and have suddenly had to go into hospital.

Dr Skelly explains:

Sometimes people with Parkinson's develop difficulties swallowing their food and/or their medication. If they have to be admitted to hospital in an emergency the doctors in the hospital may need to change the usual Parkinson's treatment to something else such as a patch or treatment through a tube in the nose. We want to investigate what we believe is a better way to help people with Parkinson’s who have swallowing problem when they are admitted to hospital unexpectedly.

We will be applying to Parkinson’s UK for a grant to find a new solution to this swallowing problem. We will need your help in developing this project but first we have to collect background information to hear about your experiences. So, please contact us if:

1. **You or a relative has been admitted to hospital and has not been able to take their usual Parkinson's medications due to swallowing problems or being too unwell, and**
2. **Your Parkinson's medication was changed to a rotigotine patch or given through a tube in your nose.**

If both apply, please contact us by email at dhft.pd@nhs.net or by phone on this dedicated number 01332 783535. Please state you are contacting us about the "Levodopa Study". Leave your name and phone number or email address. One of us will get back to you as soon as we can.

Thank you!

Dr Rob Skelly, Consultant Physician and Honorary Associate Professor / Lisa Brown, Parkinson's Disease Nurse Specialist.

2. STEPS 2 - Can electrical stimulation improve walking?

Researchers from the Salisbury District Hospital and the University of Plymouth want to understand if a small electrical stimulation device can improve walking for people with Parkinson’s. Functional Electrical Stimulation (FES) is a technique that applies small electrical impulses through self-adhesive pads. These pads are placed on the skin over nerves that supply muscles that cause the foot to lift. Early testing suggests this may help to retrain movement.

The researchers need to recruit 234 people with Parkinson’s who have difficulty walking due to Parkinson’s, can walk 50 metres with walking aids, and can stand from sitting without assistance from another person.

What is involved?

If you are eligible to take part, you will either receive the study treatment, FES, for 18 weeks or your usual care for 22 weeks. You will be asked to attend visits to your local research site which are at **Salisbury, Leeds, Swansea, Birmingham, Bangor or Cumbria**.

Those receiving the study treatment, will attend 10 visits and those receiving usual care will attend 6 visits. The length of these visits will vary between 1 and 2 hours during which you will take part in tests to measure your movement, Parkinson’s symptoms, and you will be asked to complete surveys. You will also be asked to complete a falls and exercise diary for the duration of the study. Travel expenses will be reimbursed.

Read the **participant information sheet** for more information. Then click on the Take Part Hub button below to complete the expression of interest form or contact the study team by email at **steps2.penctu@plymouth.ac.uk**.The deadline for taking part in this research is **31 August 2025** Unfortunately, those receiving Deep Brain Stimulation (DBS) or using other active medical implanted devices, such as a pacemaker, are unable to take part.

3. Help shape research on 'exercise-snacking'.

During a stay in hospital, people can lose strength and physical ability. This can be worse for people with Parkinson's, who tend to have longer stays than the general population.

Lis Grey and researchers in Aberdeen, Bath and Bristol want to see if '**exercise**-**snacking**' could be an effective way for people with Parkinson's to regain strength and function after a stay in hospital. This involves 5 minutes muscle strengthening exercises, twice a day that can be done at home without the need for any specialist equipment. Lis would like to hear what people affected by Parkinson's think about the idea of '**exercise snacking'** for people following a hospital stay. If it is seen as an important area of research, Lis will use these views to help shape a research funding proposal.

The researchers need to hear from People with Parkinson's who have had an **unplanned** stay in hospital as well as their partners, family members and carers. By 'unplanned', we mean a stay in hospital of more than one day that was not planned in advance.

What is involved? Joining an online discussion group to share your thoughts. Support is available for joining a video call

Interested in taking part? If so, click the button below to complete the registration form. If you are not able to join either of the discussion groups, but would like to know more and provide feedback by email or phone, please let us know in the registration form.

If there are any adjustments we can make to help you get involved, please get in touch with Anne at **researchinvolvement@parkinsons.org.uk.** Please express your interest by 12 pm on **Friday 22 November**.

4. IMPROVING QUALITY OF LIFE WITH AN ONLINE MENTAL HEALTH GROUP PROGRAMME

Becca Hunsdon, a PhD researcher at the University of Reading, has developed a new online group mental health programme to support the wellbeing and quality of life of people with Parkinson's (PwPs). The programme aims to provide tools to deal with unhelpful thoughts and feelings in a group setting. Beca now wants to test how effective the programme is for PwPs.

BECCA NEEDS:

50 PwPs who are experiencing anxiety or low mood who Have a stable medication regime, with no changes anticipated in the next 12 weeks, who have not accessed psychotherapy such as CBT, counselling, or acceptance and commitment therapy in the past 12 months?

Unfortunately, those diagnosed with a mental health condition such as psychosis are unable to take part.

WHAT'S INVOLVED: Taking part in a 60-minute online introduction with the researcher, Joining 6 online group therapy sessions with between 3 and 7 other participants. These sessions will last between 60 and 90 minutes, completing homework tasks between each session and surveys which will take 25 minutes to complete.

All sessions will take place over Microsoft Teams and support is available for those unfamiliar with the software. You may be asked to wait up to 8 weeks before the programme starts.

Interested in taking part? For more information, please read the *participant information sheet here* or contact Becca Hunsdon at **r.i.hunsdon@pgr.reading.ac.uk**.

To express an interest in taking part please go to *the researcher's website*, or contact Becca Hunsdon at r.i.hunsdon@pgr.reading.ac.uk. The researcher will then be in contact to discuss your participation. The deadline for taking part in this research is **30 April 2025**.

5. The LUMA study: evaluating the safety and effectiveness of a medication to delay the progression of Parkinson's.

Here is an opportunity to take part in a phase 2b study which will help the researchers at Biogen, an American Biotech company, understand how effective and safe their new drug is. The drug is called BIIB122, and the study will reveal if it can slow the progression of Parkinson's. The drug is thought to reduce the activity of a protein called LRRK2, which has been linked to the onset of symptoms of Parkinson's.

The researchers need *640 people who have been diagnosed with Parkinson's in the past 2 years, who are aged between 30 and 80 years old and have never taken a prescribed medication for their Parkinson's.*

What is involved? *First, you will be asked to take part in a full day visit to your local research centre. This will assess whether you are eligible to take part in the research. Assessments can be spread over 2 days if requested. If you are eligible to take part, you will be asked to take the BIIB122 drug in tablet form, or a placebo treatment (such as a sugar pill), every day for between 1 and 3 years. The length of your participation will be discussed with the research team after your first assessment.*

You will be asked to attend a maximum of 29 research visits, to be discussed when you meet the research team. Some of these can take place over the telephone or online, and others will need to take place at your local research site or at your home. These visits can range from 1 hour to 8 hours depending on visit type and assessments needed. The visits will include completing surveys, blood tests, physical examinations and one lumbar puncture. You can also choose to have extra tests, such as brain scans, additional lumbar punctures and genetic testing.

For more information please read the participant information sheet.

Interested in taking part? Visit the **Take Part Hub** for more information and to take part. If you have any questions about the trial please contact **clinicaltrials@biogen.com** The deadline for taking part in this research is **31 December 2024**.

Editor notes: I can't easily find out where the study sites in the UK are for this LUMA trial-they may be mostly in North America though the Participant Information sheet mentions the EU and UK with an address at Maidenhead in Berkshire.

6. CAN CBD (CANNABIDIOL) REDUCE SYMPTOMS OF HALLUCINATIONS AND DELUSIONS IN PEOPLE WITH PARKINSON'S

Around 3 in 4 people with Parkinson's will experience symptoms of hallucinations or delusions. Hallucinations can mean that the person sees, hears, or feels things that aren't there. This can be very distressing for the person and their loved ones. Current treatments for hallucinations and delusions are not very effective or come with unwanted side effects. That's why, in 2019, Parkinson's UK announced funding for **CAN-PDP,** an innovative clinical trial working with King's College, London, The trial aims to understand whether cannabidiol (CBD) may be useful for treating these hallucination and delusion symptoms in Parkinson's. CBD has been shown to have positive effects on other brain conditions such as epilepsy.

This trial needs 120 people with Parkinson's who are over 40 years old, who have experienced any symptoms of hallucinations or delusions for at least one month, have been taking any Parkinson's medications for at least one month, are not taking clozapine and have someone who can attend visits with them to a local study centre

For the East Midlands study centres are at the Royal Hallamshire Hospital in Sheffield, the Kingsway Hospital, Kingsway, in Derby or King's Mill Hospital, near Sutton-in-Ashfield.

See below for who to contact at these study centres. **The deadline for taking part is March 1st, 2025.**

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

For Sheffield contact Anna Emery or Alex Radford by email at anna.emery@nhs.net or Alex Radford alex.radford2@nhs.net).

For Derby the contact is Caroline Cheetham. Email: caroline.cheetham@nhs.net

For Sutton-in-Ashfield the contact is Sara Pisani, email: canpdp.trialoffice@kcl.ac.uk. Phone: 07936 545 178

If you have any questions, please contact th trh e CAN-PDP Research Team by email
at canpdp.trialoffice@kcl.ac.uk or call: 07936545178.

NB. The **Parkinson's UK Research Support Network** 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.

New Guide: Exercise, Brain Health and Parkinson's –

Use the link below to access a downloadable new review of exercise and Parkinson's by the Michael J Fox Foundation. Nordic walking is included as being beneficial, so it is appropriate that the September open meeting being organised by PEMRIG features two speakers discussing the benefits of Nordic walking. Use **this link** to access the MJFF site.

If you are interested in Parkinson's research and would like to be put on PEMRIG's mailing list, please contact John Turner, PEMRIG's Chair, by email at: pemrig.uk@gmail.com.

Newsletter comments, queries and submissions to the Editor at: martin69747@gmail.com.