

## **PEMRIG**

### **The PARKINSON 'S EAST MIDLANDS RESEARCH INTEREST GROUP**

#### **Newsletter – July 2022**

Hello to all people with Parkinson's, carers, families and anyone else reading this July edition of PEMRIG's newsletter. The recording of PEMRIG's Spring Research Forum on 'Improving Mental Health and Wellbeing in Parkinson's' is still available at: <https://www.youtube.com/watch?v=-16fKhcR38A>

We carried out a survey of what those who attended thought about the Forum. The results are available on the PEMRIG website which can be accessed at: <https://pemrig.org.uk>. If you have any suggestions for other forum topics, please contact John Turner, PEMRIG Chair, email: [Pemrig.uk@gmail.com](mailto:Pemrig.uk@gmail.com).

#### **What's next from PEMRIG?**

#### **JULY 20<sup>th</sup> – PEMRIG presentation to the Nottingham Parkinson's UK branch**

PEMRIG have been invited to give a presentation to the Nottingham Parkinson's UK branch on July 20<sup>th</sup> on the role of the Parkinson's RIGs (Research Interest Groups) scheme in spreading the word about what Parkinson's research is being funded and what progress is being made. Three PEMRIG members will talk with members of the Nottingham branch about PEMRIG's activities.

#### **14.00h August 9th 2022 – Online visit to a Parkinson's research laboratory**

PEMRIG are organising an online visit to the mitochondria research laboratory of Professor Lisa Chakrabati of the University of Nottingham. This will be at 14.00h on August 9<sup>th</sup> and will last about 60-90 minutes with questions. We are organising this visit so that anyone in the East Midlands or further afield can join the online visit and so find out what Professor Chakrabati's research is about. The mitochondria in some nerve cells of people with Parkinson's don't produce enough energy to power all the reactions going on in these dynamic cells and this lack of energy partly contributes to the death of nerve cells observed in Parkinson's. So Professor Chakrabati's work should be of great interest. Use this link to register for this lab visit:

<https://parkinsons-org-uk.zoom.us/meeting/register/tZlqdeCgpzMjHtfOh69WLES-zBiTdkBdRWzr>

## **September/October 2022 – Online visit to another Parkinson’s research laboratory**

This virtual visit will be to the Parkinson’s UK-funded research laboratory of Professor Flaviano Giorgini at the University of Leicester. If you wish to join the PEMRIG team at this virtual laboratory visit by zoom a link will be provided nearer the time.

The take-home messages from both these online visits will be summarised on the PEMRIG website in due course. Follow [this link](#) to the PEMRIG website to read about our previous lab visits.

## **OCTOBER 8<sup>th</sup> – PEMRIG FORUM ‘Living well with Parkinson’s’**

**‘Living well with Parkinson’s’ is the title of a day long (09.30h to 16.00h.00pm) face to face meeting that PEMRIG is organising at the Link Hotel, LE11 4EX, in Loughborough.**

This event will feature talks about some of the latest Parkinson’s research, news and trials and there will be a marketplace with information stalls and taster sessions all with the theme of ‘Living Well with Parkinson’s’. The event is aimed at working age People with Parkinson’s and those newly diagnosed but all people with Parkinson’s, carers and anyone interested in Parkinson’s are welcome to attend.

Make a note of the date in your diary and look out for more information in the next PEMRIG Newsletters. Lunch and coffee/tea will be provided.

## **RESEARCH INFO**

### **No Silver Bullet**

The No Silver Bullet group of PwP have created a YouTube channel from which you can access all the talks they have organised recently. They are worth listening to. The talk by Professor Roger Barker from Cambridge on repairing the Parkinson’s brain with cell-based therapies is very thought-provoking. The link to the site is:

<https://www.youtube.com/channel/UCN2A0vGOY6j13Ed1rV64gPQ/featured>

The No Silver Bullet talk entitled **"The current drug and research landscape in PD"** given by Dr Kevin McFarthing of the Cure Parkinson’s Trust on April 25<sup>th</sup> is now on the No Silver Bullet YouTube site above. Kevin created and updates a **"Parkinson's Hope list"** for therapies in PD which you can find at the following link; - <https://drive.google.com/file/d/1NeSyFA37b9IbUzryRRP-EqrgScjCRL-3/view>

The latest No Silver Bullet talk Dr. Alberto Espay entitled **“Matching therapies to people with the biology to benefit from them: the missing ingredient for successful disease modification”** is now online at the No Silver Bullet website above.

**Wednesday, June 29<sup>th</sup> 19.30h.** This is the date and time of the next Talk on the No Silver Bullet programme. Professor Tom Foltynie, a Consultant neurologist at the UCL Institute of

Neurology will be asking the question - "*Does the repurposing of diabetes drugs offer hope for Parkinson's patients?*" Professor Foltynie is leading the ongoing Exenatide trial, a potential neurorestorative treatment for PD. Use this link to register for this talk.

<https://www.eventbrite.co.uk/e/does-the-repurposing-of-diabetes-drugs-offer-hope-for-parkinsons-patients-tickets-356916917107>

Professor Foltynie is also the lead clinician at UCL for trials of alpha-synuclein vaccination for PD and Oxford Biomedica/ Axovant's gene therapy product for PD, and the Transeuro PD cell transplantation programme so his talk should be extremely relevant and interesting.

### **Other online research events**

The Parkinson's UK website lists several online events which may be of interest. To access the list go to the Parkinson's UK website and under the 'Research' heading scroll down and click on 'Research Events'. This should bring up a list of past and future online talks on different aspects of Parkinson's which may be of interest.

### **Parkinson's News Today**

This Newsletter is accessible at <https://parkinsonsnewstoday.com> and you can then sign up to receive copies regularly via email. Parkinson's News Today is a daily, digital news website dedicated to covering science, research and advocacy news about the disease.

### **The Cure Parkinson's Website**

Cure Parkinson's is another UK Charity which concentrates on Parkinson's Research and organising trials of potential new drugs. Its website is at <https://cureparkinsons.org.uk>.

On the Latest News page, click on 'The Science of Parkinson's Blog' and scroll down to find an article entitled 'The Road ahead: 2022' by the deputy director of the Trust, Dr Simon Stott.

### **Parkinson's UK direct link to research events**

If you want to check on what research events are coming up the Parkinson's UK website has a direct link to research events – click on: <https://www.parkinsons.org.uk/research/research-events>

### **Parkinson's UK's Research Support Network**

The Parkinson's UK Research Support Network (RSN) emails connect you to Parkinson's research and opportunities. From finding out more about research to getting involved, there's something for everyone. You can register to receive regular research emails by visiting <https://www.parkinsons.org.uk/research/get-involved-research> and clicking on "Join the Network."

## **PARKINSON'S TRIAL NEWS**

## THE INSIGHT-PD STUDY

PEMRIG has learned about a new trial 'The Insight-PD Study being run at the University of Nottingham by Dr Tayyib Hayat MRCP PhD, a neurology Clinical Research Fellow.

In technical terms the project will investigate '*In vivo serial neuromelanin MRI to assess depigmentation rates in the substantia nigra of early Parkinson's disease*' as shown in the accompanying poster.



Dr Hayat is particularly looking for people in the early stages of Parkinson's who have been diagnosed in the last 2-3 years.

The study lasts for two years and will involve MRI scans. You can get in contact with Dr Kayat for the Insight-PD description sheet by emailing him at [tayyib.hayat1@nottingham.ac.uk](mailto:tayyib.hayat1@nottingham.ac.uk)

## NORDIC WALKING AND PARKINSON'S

Sarah McCracken, a Parkinson's nurse at Queen's Medical Centre, is conducting a trial to see if Nordic walking can improve posture and stride as well as other features in people with Parkinson's. She is still recruiting for this trial and participants receive a quality set of Nordic walking poles to keep.

You will be offered tuition on "How to Nordic walk" over 8 lessons to embed the knowledge. Sarah will record some physical measurements, eg Timed up and go from a chair, a ten and 20 metre walk test and a TRAGUS measure for posture. She will also ask you to complete a non-motor scale questionnaire for Parkinson's; looking at areas like fatigue, sleep, constipation, mood, pain, a well-recognised tool in Parkinson's research. She also records field notes during the classes eg. Weather conditions, busy class, group support, etc. These measurements will be repeated after 8 weeks, 6 months and 9 months.

The trial is held at the Lakeside Arts cafe, Highfields park, University Boulevard, Nottingham, NG7 2TQ on a Thursday afternoon for 8 weeks. Classes are at 1pm or 2.30pm and involve initial tuition and warm up exercises followed by practice by walking round the lake at Highfields Park and warm-down exercises.

If you are interested contact Sarah for the participant information sheet and other details by email at [sarah.parkes007@gmail.com](mailto:sarah.parkes007@gmail.com)

## SPEECH RESEARCH OPPORTUNITY

*Could you help other people with Parkinson's by recording your voice reading a few paragraphs and talking about your hobbies or interests?*

Paul Gadd, Director of Protocol IT, is looking for volunteers with Parkinson's to help record some speech to create an Artificial Intelligence network for converting speech to text.

He is undertaking a project to train a neural network to convert speech to text for those living with Parkinson's Disease. He is based on the campus at Loughborough University and is seeking volunteers from those living with Parkinson's whose speech might be suitable for recording to then help train a neural network to learn how to interpret slurred or difficult to understand speech. In order to train the neural network, he needs to obtain 600 hours of speech from 30-40 PwP over the next 6-12 months to provide enough accuracy.

Recording can either take place on campus Loughborough University, or he can visit your home to record your speech for about 30-45 minutes, then return every 3-4 months to record changes to your speech. If you are interested in taking part, please email [info@protocolit.co.uk](mailto:info@protocolit.co.uk) or call 01509 278645.

More details are available at: <http://www.protocolit.co.uk/parkinsons-speech-research/>

## **MORE TRIALS URGENTLY RECRUITING PARTICIPANTS NOW**

### **Balance and falls.**

A phase 3 clinical trial of a sticky medication patch for falls in Parkinson's (CHIEF-PD). It has 3 months left to recruit around 300 participants. [Learn more about the CHIEF-PD trial.](#)

### **Daily living and drooling.**

A trial of a wrist-worn device assisting daily life of people with Parkinson's as well as seeing if it can manage drooling. We have 4 months left to recruit around 3,000 participants. [Find out more about the device and drooling trial.](#) This trial is also looking for **anyone with Parkinson's** to trial the device. [Learn more about the general device trial.](#)

### **Hallucinations**

A trial looking at repurposing an existing drug to see if it can help with Parkinson's hallucinations (TOPHAT). It has 20 months left to recruit about 250 participants. [Find out more about the TOPHAT trial.](#)

### **Anxiety**

A study looking to better understand anxiety in Parkinson's (AND-PD). There are 9 months left to recruit around 130 participants. **The study is looking for people with and without Parkinson's.** [Discover more about the AND-PD study.](#)

### **Low mood**

A trial to test a potential treatment for low mood in Parkinson's and to see if it can slow the progression of the condition (ADEPT-PD). It has 10 months left to recruit around 300 participants. [Learn more about the ADEPT-PD trial.](#)



<https://doi.org/10.3390%2Fbiom9070271>

The article describes many of the food supplements we take and discusses the results of studies investigating the value of most of the common supplements including *n-3* fatty acids., N-acetylcysteine, flavanoids, etc.

## **Nicotinamide riboside supplement shows promise as a potential therapy for Parkinson's disease**

A new Phase 1 trial of nicotinamide riboside (NR) has just been published and shows promising results. The link to the work is at: <https://doi.org/10.1016/j.cmet.2022.02.001>

The main findings are that oral NR increases brain NAD levels in individuals with Parkinson's disease, NR intake alters cerebral metabolism in Parkinson's disease, and that cerebral NAD increase is associated with clinical improvement in Parkinson's disease. A youtube video discussing the results and highlighting the importance of NAD/NADH in energy metabolism can be found at <https://youtu.be/C5nXAUgsOXM>

## **Parkinson's UK – Virtual Biotech**

A recording of the 'Accelerating Research Lecture - 5 years of the Virtual Biotech' is now available to watch online, highlighting Parkinson's UK's drug discovery work as well as the TopHat clinical trial and the partnership work with UCB Pharma: <https://www.youtube.com/watch?v=M72TNxavtR8&t=1s>

## **CONTACT US AT PEMRIG**

We welcome ideas and suggestions for speakers and meeting themes so please get in touch via our website or email. Forward any items for the PEMRIG Newsletter to the Editor below at [martin69747@gmail.com](mailto:martin69747@gmail.com)

John Turner, Chair, PEMRIG Email: [pemrig.uk@gmail.com](mailto:pemrig.uk@gmail.com)

Martin Rumsby, Newsletter Editor

The PEMRIG website can be accessed at: <https://pemrig.org.uk>