

## MINUTES

### **DRIG Steering group**

Minutes of Meeting No: 2021/02

**Date/time: 17<sup>th</sup> March 2021 via Zoom, 15.00 – 16.30**

Location: Online

#### **1. Apologies, Minutes of Previous meeting and matters arising**

Apologies from Andy Howden.

Follow up to last meeting – minutes are now put up on DRIG website here:

<https://www.drig.org.uk/steering-committee-minutes>

#### **2. Update on the Technology Event no 2 (participation and output) and No 3 (preparation)**

Event no 2 - Really pleased with the number of participants, around 120 for the talks, but once we went into break-out sessions dropped around 80. Some people did seem to think that it didn't get enough publicity, but PUK used all of their usual channels. In general, extremely successful event, no reason not to believe we won't get as many for the third event. Only 66 sign ups so far – possibly because PUK Research Round-Up is going out later this month, on the 24<sup>th</sup>. It has also gone out in the Scotland Volunteer Bulletin today. JM will send this around all of the Fife group.

Planning for third event – format is more or less the same, a little more complicated at the end as we are having more speakers. Possible to have Rory CJ make some closing remarks and a 5 minutes session from Paul MA. Also, a 5 minute video presentation/interview about the World Parkinson's Congress. A

Werner has also invited all of the speakers back to answer questions if there are any – but not as a panel, just available. Might be better to make this a more concentrated session, we don't necessarily need all of the speakers from the 3 sessions available to answer, but ask those with questions on the earlier sessions or anything that occurs later to forward them to the SIGP@T address. This might also help us to plan future events. Will be sending out a questionnaire for participants to complete after the final event, for feedback.

Need another short discussion on practicalities Thursday 25<sup>th</sup> at 16h  
John will do script as usual, which is very useful for all of us.

After discussion felt only one 'celebrity' needed. Paul MA will be coming anyway, so easiest to ask him – 10 minutes to give his usual humorous take as a PwP and possibly add his own view of the 3 events. Once panelists list is

finalised should be forwarded to Liz for zoom preparation and sending out invitations.

### 3. Where do we go from here on Technology?

We should wait for the third event before we decide this, but clear that there is a desire for some form of easy technology to keep a clear record of symptoms (physical and mental if poss) and the patient's environment

### 4. Future events – Melissa McConachy, PD Warriors, PD & the gut was an earlier idea, any other ideas?

Janet – been reading about Keto diet, she is on week 2 at the moment. It would be helpful to have something on this diet in the session on PD and the gut. It would be very helpful to organise a general event on drink and food. Brendan - Symprove drink is another example that could be included in here. Janet, Brendan and Ron, who has some ideas from the Glenrothes coffee group, will look into what could be included in a Gut event. We should also include Prof Maria Doitsidou, from Edinburgh, who is a very good speaker (Liz N has her contact details) and Esther also happy to speak to invite her.

<https://medium.com/parkinsons-uk/diets-for-parkinsons-research-explained-edfc17a99d12>

Also, a regular event on exercise would be useful – possible ideas for this year: PD Warriors (<https://www.insightintopd.com/>), brain gym etc. other exercise courses. Subgroup of Jo, Janet and Brendan, with support from Chloe, Julie Jones and Amanda Mckay can help find experts in a variety of physical activity types.

Esther - possibly someone could be involved from the lab on providing info on evidence based exercise or diet results – MJFoxF has a very good resource on food and diet on their webpage.

Other RIGs' events coming up – useful for ideas and also to avoid repetition:

Saturday 17 April, 10.30am: Please join the **East Midlands RIG** as they hold a Spring Research Event on 'improving **physical and mental health** for people with Parkinson's'. Keynote speakers include Dr Bhanu Ramaswamy OBE (exercise for people with Parkinson's), Dr Rob Skelly (investigating the benefits of physiotherapy at different stages of Parkinson's) and Dr Jennifer Foley (mental health and Parkinson's).

You can read more and register to attend online here:

<https://www.eventbrite.co.uk/e/improving-physical-and-mental-health-for-people-with-parkinsons-tickets-143103140345?utm-medium=discovery&utm-campaign=social&utm-content=attendeeshare&utm-source=strongmail&utm-term=listing>

Saturday 10 April, 11am: Please join the **South East RIG**, Medway Groups and the University of Kent, as they hold a World Parkinson's Day Lecture on research and exercise. Speakers will talk about research engagement and

participation, **the therapeutic effects of exercise**, and how dance can help people with Parkinson's. There will be emphasis on opportunities for people in Kent and East Sussex, but all are welcome!

You can read more and register to attend online here:

<https://www.eventbrite.co.uk/e/world-parkinsons-day-lecture-research-exercise-tickets-141810989487>

## 5. Other ideas we would like to follow up:

Possibility of a **glossary of terms** for the DRIG Website.

A talk from one of the Dundee lab scientists about something they are doing in the lab then have the talk given by a layperson on what they have understood of the talk.

John - would prefer to have a talk where we can listen and interrupt as soon as we are not following very clearly. This could help to find the words for the glossary.

Christine – would really like to see a page or two of words and their definitions explained in laymans language, especially useful for people who are new to Parkinsons.

Esther - very useful to do this and would like to be involved in helping to put things into lay language. Brendan interested in creating glossary – create another sub-group with Marc, John and Christine, which John will co-ordinate.

## 6. Any updates required to the DRIG website – eg update on research opportunities, any more researcher interviews?

Esther will email a number of trial opportunities which could be coming up  
Andy will look out for any of the researchers who would be willing to be interviewed and then we will find a member of the Steering Group who would like to be involved in the interview

## 7. Update on PD Avengers Scotland

Marc is going to be lead the **Research arm of PD Avengers**, which aims to have PWP's at the core of decisions about research and trials. He will keep us updated on what is going on here.

Recent event with Larry Gifford talking to the four writers of the Ending Parkinson's book. <https://twitter.com/giffordtweet?lang=en>

This was recorded, took place yesterday, red letter day – aiming to send 10,000 red letters to Jo Biden, complaining that not enough is being spent on PD.

Lots of people from around the world expressed an interest in this campaign.

Brendan – Boris Johnson's mother suffers from PD, should we be doing the same in the UK? Marc would like to see it being done in a similar way in France, Spain, Germany etc.

It is a standard letter, currently only in English, that would be easy for us to re-use for a UK based campaign (Scotland and UK).

Tanith Muller could give us advice on how to set up a national letter writing campaign.

## 8. AOB

**Fund raising event by Dundee University** some of us will be asked if we would like to participate in this event, this is specifically raising money for Dundee University PPU. We cannot be involved through the DRIG steering committee, nor through our association with PUK Branches and Groups in fundraising for any specific research unit such as the PPU. Individual fundraising is possible.

Brendan - what sort of amount of money are we talking about to have real impact on the PPU lab? Several million, so would it be country wide?

John – assume that they will focus on those who came to an earlier dinner event that John and Marc were involved in, approaching major funders – fund managers, wealthy people looking for things to do with their money etc.

**Glasgow Research Interest Group Event:** April 14<sup>th</sup> 2:30, look out for event sign up details, speaker Andy Kerr.

**World Parkinsons Day** See <https://www.parkinsons.org.uk/get-involved/world-parkinsons-day-2021> for info on World Parkinson's Day

**Update on existing treatment** would be helpful to have an update at our next meeting on new treatments. Esther would be really happy to provide an update on this. Really exciting work going ahead in various fields, could highlight a couple of things published in journals. She will run it by Pierre.

Announcement at Sheffield for a virtual biotech project £1.2M to be invested.

See website: <https://www.parkinsons.org.uk/news/were-investing-ps12m-drug-could-slow-parkinsons>

Manchester University, funded by MJ Fox Foundation – the new diagnostic tool via Joy's smell test: <https://www.parkinsons.org.uk/news/scientists-move-closer-developing-game-changing-test-diagnose-parkinsons>

### **New Student in the Lab:**

Student from University of Yale, Caitlin Brown, has started to work with Dario, would like to have a link into PwPs with someone from DRIG. Brendan and Marc would be happy to get in touch with her, Esther will send details and facilitate a meeting.