

## MINUTES

### **DRIG Steering group**

Minutes of Meeting No: 2021/02

**Date/time: 10<sup>th</sup> of May 2021 via Zoom, 10.45 – 12.00**

Location: Online

Present: Marc Van Grieken, Liz Nash, Chloe MacMillan, Brendan Hawdon, Werner Remmele, Ronald Page, Janet Kerr, Esther Sammler, Andy Howden, Jo Goodburn

Apologies: Pierre and Christine Descouts

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

Approved previous minutes, matters arising addressed below

#### **2. Follow up to the Technology Events – Digital Parkinson's**

Documents have been circulated from the Digital Parkinson's (DP) first meeting on the 5<sup>th</sup> of May, all present at that meeting accepted the formation of the group (30 members, 11 from the UK, including Rui Couto from Portugal and John Dean from the States, both involved in WPC) and the desire to make it a fully international group.

They agreed that tangible projects, and not too many, should be the goal. All volunteers so need to be realistic about what can be achieved.

Standardisation – importance of digital data obtained remotely being properly accredited by authorities who would need to agree to its use, eg in drugs trials etc.

Thanasis Tsanis joined in last 15 minutes and added idea of a project with PwPs using monitors which could feed back to his lab and, via an algorithm, assess progression. TT is writing a project proposal (first draft) which will include Digital Parkinson and would like support from ERIG and DRIG – he is looking for 50 to 100 PwP participants.

On modelling, Werner very keen to create a sub-group on modelling the progression of PD – difficult since different trajectories for different people. Chloe mentioned the research being conducted by Dr Carl Counsell in Aberdeen and Dr Donald Grosset in Glasgow. Both research projects have been operating for several years and both are looking at how Parkinson's progresses over time. As far as she knows, their research isn't focussed on apps or tech; however, their findings still might be useful.

Next step – launch a questionnaire to the DP participants on how to go forward. Marc is suggesting that this group could work under the Research arm of PD Avengers on specific topics eg the Thanasis project. Marc will bring this to the PD Avengers Research meeting tomorrow.

### 3. Future Events

**PD and the Gut:** Janet currently in week 11 of trying the Ketogenic diet, because she had read that it is beneficial for people with PD, not many PwPs seem to have heard of this. She has a list of people who could be expert speakers in this field eg Dr Nick Norwitts, but wondered if we have a standard DRIG invitation letter for this purpose?

Marc – we need to have a clear brief of what the exact aim of the event would be and the field to be tackled before we start to approach potential speakers. Brendan pointed out that they have discussed this in young PD group, sharing knowledge on specific food and food groups would be really helpful. Esther pointed out that there is not much information available so it would be good to do a trawl of the research already available, Janet has looked on the web and found a few doctors, including Dr Patrick Moore. Esther could ask her medical student to demonstrate to Janet how to use 'pubmed' to find all of the papers and publications of research in this field, to ensure that we have evidence at the right level. Janet agreed that this would be very helpful. Brendan noted that the Lancet article published on WPCDay (Bloem and Klein) is useful for such references.

Brendan also suggested that Prof. Chaudhuri of Kings College London on the clinical trial of Symprove could be a useful link and would be about a PUK trial. Agreed that Janet and Brendan will take this forward to produce an outline idea for our next meeting. Useful links added to the zoom chat box on this topic:

[https://files.michaeljfox.org/041819\\_MJFF\\_DIET\\_GUIDE.pdf](https://files.michaeljfox.org/041819_MJFF_DIET_GUIDE.pdf)

<https://www.michaeljfox.org/news/updated-guide-diet-and-parkinsons>

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

[https://parkinsons-org-uk.zoom.us/webinar/register/WN\\_oD-twmpQayDHlCr\\_mXlGQ](https://parkinsons-org-uk.zoom.us/webinar/register/WN_oD-twmpQayDHlCr_mXlGQ)

**PD and Exercise** – JG to take forward preparation for an event on exercise which gathers PwPs who are prepared to share their experience on the usefulness of different types of exercise in terms of how much they do and the effects on their PD symptoms etc. Also include update on trials and literature, initial contacts should be with Julie Jones and Amanda McKay

### 4. PD Glossary from the RIGs

Everyone likes it and thinks it would be good to put it up on the website, in a format which will allow additions and editing.

### 5. Updates required to the DRIG website – eg update on research opportunities, any more researcher interviews?

- News on WPC to put up and Caitlin Brown's article:
- A link to highlight Mark Cox's poetry book
- Update to the research page which Esther will get organised this week, lots of new projects coming up.
- The lab also has a couple of exciting new pieces of equipment, mass spectrometer and, in particular, a good piece for the website could be a

video of the new analytical robot. This robot is hugely advantageous for the lab for ensuring that technical errors in a large set of testing are as small as possible. The robot is tackling both dementia and Parkinson's. Andy H will coordinate the video of the equipment in the lab and Esther's post doc student can help with the ultrasound scanner could be done with Tom Gilbertson, it is being inaugurated in early June

How do we get more people signing up to our website – Esther suggests that we should have a small info sheet which explains what DRIG does and how to get onto the site and find out information, this could be given out by the Parkinson's nurses and also with the info pack which goes out for a first clinical appointment. Also consider printing DRIG business cards.

#### **6. Possible joint project with the SE England RIG**

JG explained a bit about this project, and that at present it is really too complex for mass use, but we will aim to collaborate with Lee and Mike. Marc pointed out that a subgroup of the Research arm of PD Avengers works on projects built by PwPs – so this may also be a good contact.

Janet also talked about a questionnaire she has been sent on when and how you take your medication and a way to measure whether your medication is really having a positive effect, this may also be useful, see questionnaire:

[https://www.parkinsonsmeasurement.org/toolBox/pharmacokinetics.htm?fbclid=IwAR1fQEMLBjdbVzCy3d6ytw\\_oSIVu7Kg0XmB8M4Xue6P\\_Zu7xaZKWdkbOwc](https://www.parkinsonsmeasurement.org/toolBox/pharmacokinetics.htm?fbclid=IwAR1fQEMLBjdbVzCy3d6ytw_oSIVu7Kg0XmB8M4Xue6P_Zu7xaZKWdkbOwc)

#### **7. AOB**

**Fund raising event by Dundee University** the 30 day challenge, for further fundraising for the lab. MRC PPU is also becoming a formal partner of the PD Avengers. There can also be confusion between what PD Avengers, Cure Parkinson's and Parkinson's UK all stand for. Want to have a major event at the end of May with Dario, from the lab, Larry and Sonia founders of the PD Avengers, DRIG members, Brendan and Marc, Esther. This event would also promote the 30 day challenge. People will take part in the challenge as individuals, there is a central fundraising page of the university where you can create your own profile for any fundraising you can propose.

There will be a cycling team, including Brendan, Marc and Janet, who suggests a goal that everyone's distance could be added to. Andy will be swimming, cycling and running – all for 30 days!

Website to make your own fundraising profile: <https://www.dundee.ac.uk/parkinsons>

The Just Giving site is separate here:

<https://www.justgiving.com/campaign/parkinsons>

**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** 1<sup>st</sup> of May LRRK@ A and B clinical trial – moving forward with combined phase 2 and 3 clinical trial in a negotiation to possibly bring this to Dundee. Esther could write a short update on this for the DRIG website.

**Formal Review of Positions in the Steering Group** – when do we have to change the key positions? No formal rules for RIGs, up to us how we share those positions and responsibilities. We do have some Terms of Reference, which Marc and Jo will look out and we can come back to this at our next meeting.

**Fantastic video** that Esther added in chat box – do watch, I won't forget what phosphorylation means!! <https://www.youtube.com/watch?v=IGmfq6UXQLk>