

MINUTES

DRIG Steering group

Minutes of Meeting No: 2021/02

Date/time: 3rd of August 2021 via Zoom, 10.00 – 11.30

Location: Online

Present: Marc van Grieken, Liz Nash, Chloe MacMillan, Brendan Hawdon, Werner Remmele, Janet Kerr, Christine and Pierre Descouts and Jo Goodburn

Apologies: Andy Howden, Ronald Page, Esther Sammler

1. Apologies, minutes of Previous meeting 10th May 2021 and matters arising

Marc introduced us to Molly Wilcock, a fellow PWP, diagnosed 9 weeks ago, who is interested in hearing more about RIGs.

2. Fundraising

Dundee University ran a fundraising campaign during June 2021: the 30 day challenge. It is understood that approximately £37,000 was raised as part of this campaign. This money was raised for Parkinson's research and will be spent by Dundee University at their discretion. Also see Appendix 1 for an explanation about the PPU specific account.

Jo also advised the meeting that Andy has further ideas for fundraising under the name "Source to Sea: Tay in a Day"! Walking, hiking, biking and kayaking the Tay. All supported this idea and look forward to getting more info from Andy about possible timing etc.

3. Future Event with North of Scotland Parkinson's RIG (NoSPRIG)

A brief discussion was held about the planned event with Dr Tom Gilbertson on the new Focussed Ultrasound equipment. It was stressed that the language used should be pitched at the right level for us all to understand, John has heard him speak before and thinks he would be an excellent speaker to explain this. Thursday 14th October at 6:45pm is possible date, this being the week following the annual Edinburgh RIG's meeting, Jo to follow up with Andy and Tom and Liz will pass on this proposal to the NoSPRIG meeting next week.

4. Co-operating with the other Scottish RIGs:

Marc suggested that to potentially streamline communication the Chairs of the RIGs could attend each other's meetings to help with coordination between the Scottish RIGs. Liz will help to co-ordinate this and we could also share our agendas with all UK RIGs, for comment or input.

5. Future Events:

Brendan and Janet have been working on this and are going to meet soon. Brendan has created a list of all of the PUK funded research going on in this area of the gut. He proposes inviting two of the Principal Investigators to come to discuss results of their work, a good one

would be the Symprove trials that are going on and probably Maria Doitsydo (if we use her check that she is happy to have it recorded). Other possibilities: Anna Bruce is dietician and nutritionist, British Dietetic Association; Richelle from Ireland is a dietician with PD herself. Aim to set this session up for mid-November, weekday early evening.

6. Update on PD Avengers (PDA) Scotland and PDA Research branch:

Marc now chairs the Research arm of PDA and Brendan has joined the group.

Will be looking at more patient and public involvement in research. Should be careful that PUK and PDA do not duplicate things being done, Liz suggested that Natasha Radcliffe at PUK who leads on PPI would be a very useful contact on this. Marc quickly ran through his presentation on the Mission, Objectives and Pillars of PD Avengers (copy attached).

John concerned that PUK local groups need more information about what is going on in the research area within PUK. He would propose that some sort of information pack on what is going on in the various avenues of information flow from PUK. Janet pointed out that the PUK 'Research Round-up' regular email for members of the Research Support Network fills this role quite well. Liz confirmed that this is what gives you regular updates, not only on PUK research funded projects but research around the world, as well as research events and requests for participation in studies etc. Liz will prepare an A4 sheet on all of this.

7. Future meetings:

Should we try to restart the idea of meeting in person? Some of us are keen to do that, others would prefer to remain on the zoom, so meetings should be hybrid, but with careful planning to ensure that those coming in by zoom can participate fully. We would need to find an appropriate room, Jo to check with Andy if the lab has a room, possible date would be the **13th of September at 3pm**. If not possible to do it at the university then we will try the No 10 meeting venue. We first have to be sure that we can comply with the PUK guidance for in person meetings. Liz noted that you have to comply with local government guidance and complete the PUK risk assessment. John has used the PUK toolkit for getting back into in person meetings (copy attached). We would also have to make sure that we have taken account of everyone's preference for attending the meeting.

8. AOB – some info from Liz:

- A UK-wide online event for the whole Parkinson's community (PwP, loved ones, healthcare pros and researchers) - 19, 20, 21 October: <https://www.digitalevents.uk/par-con-2021/> -- will feature an exercise session, gut/diet session, and others - focused on research and taking tips from research to live better with Parkinson's.

- You can now find a recording of last week's Edinburgh stem cells lab tour with Dr Tilo Kunath online here:

https://drive.google.com/drive/folders/13-BKGZTYyfoSc5IAIct-HH_qfRwXVfkK

Appendix 1: fundraising for the PPU

Since fundraising in 2017 and 2018 by Marc a separate account has been established within Dundee University which is administered by Paul Davies general manager of the MRC PPU. The reason for this was that Marc had specified that 50% of monies raised through the fundraising should be allocated to Parkinson's UK and 50% to the MRC PPU.

The monies so raised for Parkinson's UK will be allocated by Parkinson's UK and DRIG has no involvement or influence on this.

Money raised specifically for the PPU and in this special account administered by Paul will be spent (formally) at the discretion of the PPU subject to it being on research. However because fundraising for this particular account has almost exclusively been done by members of DRIG, Paul and his colleagues would appreciate involvement of representatives of DRIG in decisions regarding the spending of these funds. A small local grants committee has provisionally been established comprising Paul Davies, Marc van Grieken and Tiloh Kunath of Edinburgh University. Marc has drafted terms of reference for this and once agreed will circulate these. It is this committee that would ask for opinions from DRIG.

Although the process is quite formal, in practice we can deal with this in the same way as we have done to date: Esther, Miratul and Dario contacted us several times to ask if we were able to support summer placements for students at the PPU. In the first year 2019, this funded 2 summer placements and some of you may recall that each of these gave a presentation at the end of their project. Last year 2020 going into 2021 this funded Molly Rickwood who has been writing a blog. Recently we confirmed funding support for Claire as part of a six-month placement from Yale University.

Currently there are applications for three students summer placements, one from Miratul and 2 from Esther. Each of these placements requires approximately £2,000 of support. At present there is approximately £25,000 in this account. That is not all from fundraising but also includes donations made directly to the PPU and some of these donations are already allocated but not necessarily spent.

This account is also used for receipt of donations specifically made in support of particular researchers or research projects at the PPU and is used for money from fundraising by individuals who wish to allocate the money they raise to be spent within the PPU.