

MINUTES

DRIG Steering group

Minutes of Meeting No: 2021/04

Date/time: 13th of September 2021 via Zoom, 15.00 – 16.30

Location: Online

Present: Marc van Grieken, Liz Nash, Chloe MacMillan, Brendan Hawdon, Werner Remmele, Andy Howden, Christine and Pierre Descouts, John Minhinick and Jo Goodburn

Apologies: Janet Kerr, Esther Sammler and Ron Page.

1. Apologies, minutes of previous meeting 3rd August 2021 and matters arising

Apologies from Janet Kerr, Esther Sammler and, post meeting, we were glad to hear from Ron Page.

Minutes of last meeting approved and noted that they should be posted on the DRIG website – action JG.

2. Update on future event with North of Scotland Parkinson's RIG (NoSPRIG)

We will report back on this discussion to the NoSPRIG tomorrow. Brendan pointed out that Dr Nir Lipsman who is based in Toronto and who first introduced Focussed Ultra Sound (FUS) as an alternative to DBS has not confirmed if he is willing and able to give a talk to the DRIG / NoSPRIG event on the recently installed FUS scanner in Dundee. This event is scheduled for 4.30 pm to 6pm on 14th October. The idea is that his talk would be followed by the detailed description of the machine in Dundee, by Dr Tom Gilbertson. Marc has taken on to try to contact Dr Lipsman, possibly via Soania Mathur of PD Avengers who is also based in Toronto.

Andy explained that Tom will be live at the event for answering questions but, at the moment, it doesn't seem to be possible to have someone discussing the machine with him, getting access to Tom in the hospital would be difficult. Rather he will show pre-recorded material on the machine in action. He could then do an introduction, followed by videos of the machine, then live Q and A.

We would need a chair to keep things in order – Liz as host can also mute people as required. Introduction of the event, for say 3 minutes, then Kismet or Esther would introduce Dr Lipsman and Andy would intro Tom Gilbertson. Andy and Brendan to finalise running order. Possible change of time to 16:30 instead of 18:45 – Post meeting Andy confirmed with Tom Gilbertson that he is available between 4.30-6pm.

Possibility of inviting NoSPRIG to do the thank you and ending of the event. We should also circulate the draft programme to ERIG (David Melton 7th Oct) and GRIG (Colin Williams 23rd Sept) – Jo will take care of doing this. The ERIG annual talk now attracts about 1200 viewers.

Post meeting Jo and Marc joined the NoSPRIG meeting on 14th Sep, and Andrew Grant, who proposed this event would be very happy to close the meeting, with a quick resumé and thank the speakers. Brendan and Andy will keep Andrew G in the loop on the proposed running order draft. It was really nice to meet the members of NoSPRIG and they were also enthusiastic about trying to

ensure we coordinate our work to avoid repetition and to collaborate on how we use the potential speakers etc.

3. Co-operating with the other Scottish RIGs:

This has been discussed to some extent by the item above and Jo and Marc will report back following NoSPRIG meeting. We will also touch on a series to run together on diet and the gut.

It might be helpful to keep a paper on the events planned to avoid duplication etc. Perhaps we could do better coordination across Scotland, important not to add work to the volunteers' jobs, but would help to know what is going on in other RIGs.

Liz already has created an excellent document with all of the UK RIGs upcoming events listed, this will be an invaluable tool in better inter RIG coordination. You can access it here:

https://docs.google.com/spreadsheets/d/1Za0IqSLCKQ4_oaxTnz1hS5fbHbSjhyWnnzxrUgrqjds/edit#gid=1978215435

4. Future Events:

Parkinson's and the gut: Brendan and Janet, Janet has given her apologies for being rather busy due to her court case and will be back in action with us when she has more time available. Liz pointed out that it is not at all a vital part of the RIG responsibility to be running events all the time, there are very many research events available so we should not feel bad at all if we are not constantly producing new events. Marc pointed out that these ups and downs are the reality of PD and our group is a reflection of that. Brendan also pointed out that we should avoid a proliferation of events – we should not saturate the interested community. This again points to the need for a comprehensive work plan. Also, regular updates on Special Interest Groups.

Brendan added that the gut is a constantly evolving topic and there are several on-going PUK funded projects which could make for very interesting topics, but Brendan is having trouble getting responses from those people, at the moment.

Jo mentioned keeping the Exercise annual topic idea to the fore – possibly to share around the 4 Scottish RIGs on an annual basis.

Marc suggested that Brendan could perhaps draw up a half page broad-brush workplan.

John would still be keen to ensure that we work on getting speakers to talk at the right level for non-scientists to understand the incredible work that is going on. Andy agreed to take this point to Tom Gilbertson and ensure that he will make it very accessible and talk in lay terms – best to err on the simplification side.

5. Patients involvement. Marc explained that so much more effort is now being placed on putting patients at the centre of the activities of many organisations' actions.

The latest he has been contacted by is called 'Patients in Focus' based in Denmark and established by a EUPATI Fellow. PinF is not targeted at PD but covers all disease (areas) There are a lot of organisations working in this field (some exclusively for PD) so rather confusing, as all seem to be claiming to do the same thing. Huge network, so easy to get drawn very deeply into it without necessarily knowing which place is the best place to be.

Marc will send more information round about this, and would welcome anyone who might want to follow up on this.

John mentioned a paper from the ERIG, which was published, on topic of the patient being part of the analysis of the patient, keeping good records of how you are is so important.

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

The University of Dundee and the MRC PPU are now official partners of PD Avengers. See attached screen shot of partner organisations from the PDA's website.

Marc and Brendan have meeting tomorrow with the Research Branch on liaisons and bringing in more people – Brendan helpfully drafted a work programme, which is very useful to provide some focus. The organisation itself is reviewing its governance structure and proposals for the internal governance are expected shortly.

PDA also pursuing some other powerful projects, eg Women and PD – going for a big grant from MJFox Foundation. Also working on People and patient involvement, Marc represented in this via EUPATI and also looking at fair market value in relation to patient involvement.

In general, PDA is still looking for new members. Found some in both Belgium and the Netherlands.

7. AOB:

Marc confirmed he is representing EUPATI on the Patient Focussed Medicine Development (PFMD) steering group for Fair Market Value (FMV), which will discuss remuneration for PPI.

Andy is quite keen to try out his 'River Tay in a Day' project as a big fundraiser – can be a hike, a bike or a canoe, or a bit of all three. It's tricky to plan as it is very weather dependent. The University are interested in being involved. It will be for next year. The money raised by the University in the month of June this year is now being spent and Andy has to provide a report on how the money is being spent, which he will share with us.

Marc suggested that we should invite both Mollie and Claire, research students who had their placement funded by DRIG, to report back on their lab experience.

John showed us his graph of what percentage of Parkinsons patients in Fife are members of the Fife support group – seems, at best to be about 15%, given that some of the members are family/carers.

Jo also mentioned that we are not getting new members from the DRIG website either – other than requests from Russian Bots!

Upping local group membership is something that we could consider as another goal, perhaps getting John's equivalent from the other local groups to Dundee, eg Tayside and Perthshire, involved in our steering group would be useful.

Date and time of next meeting:

Provisional date **Monday 6th December 15:00.**
