

MINUTES

DRIG Steering group

Minutes of Meeting No: 2021/01

Date/time: 12th January 2021 via Zoom, 10.00 – 11.30

Location: Online

1. Apologies, Minutes of Previous meeting and matters arising

Apologies from Esther, Janet, Chloe and Brendan. Marc asked us all to share a recent happy moment with the rest of the group – a nice positive way to start the meeting.

On the minutes Marc suggested that we put the agenda and minutes of our meetings on the DRIG website. JG to action this.

2. Update on the Technology Event no 1 preparation and participation (this was a brief discussion of the key speakers for the event)

Currently 95 registered participants, plus 10 speakers. Liz will send a reminder around the RIG and research community with the Eventbrite invitation. After discussion decided that best medium, given numbers and the Q & A panel, we will go for Webinar, to ensure that we can have all the panelists on the screen together. We will ask people to raise questions before the event. During the conference we will still ask people to add questions until the end of the break. Liz, Jo and Marc will do some filtering of the questions for John to use and we will ask the speakers to look at questions on their own parts. Werner will contact each speaker to find out exactly how long they will speak for and, if time, ask them to take some questions directly after their talk. Marc to make the timing doc a bit more specific. RCJ's conclusion should be 5 minutes max. We should ask all of the speakers to log in half an hour before to check all the IT issues.

In the main meeting John gave an overview of where we have got to in the preparations.

3. Preparations for Technology Event no 2 – all suggestions welcome

Managing Daily Life with Parkinson's – participants will be asked to complete a grid with the symptoms and problems that are an issue for them. This will allow us to have a really clear idea of which are the key symptoms where technology could help with everyday tasks.

Liz told us that Julie Dodd and her team have a library of apps/technology available which she could explain. Also try Emma Lawton, left Parkinson's UK now, still very involved in health tech and worked for Parkinson's UK she may be able to help and Liz believes would be a good speaker.

Andy will ask Esther and Miratul if they could take a look at the table for any other suggestions. Also suggestions for potential speakers.

Marc will contact the University of Nijmegen in the Netherlands.

We could also ask participants at the first talk for their priorities for next talks via a poll on what they would like to hear about – Werner, Liz and Andy to prepare.

On the title for second talk we should make it clearer that it is about living with your own individual difficulties caused by Parkinson's

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

Andy suggests that to get more researchers involved we could ask that lay abstracts could be provided on any papers published. JM and MvG to do more on assisting researchers to put work into lay terms

We could also interview researchers who work with other DRIGs.

5. Update on PD Avengers Scotland

Now have active campaign to circulate a one page letter inviting people to sign up to the Scottish PD Avenger Hub, aiming to get 1200 sign ups before end of January. Can this be distributed to RIGs and research volunteers – yes and Liz will ask if it could also go via a RSN email

6. AOB - nothing