

Minutes of Epilepsy Consortium Meeting held on 28 October 2020

Via Zoom

Attendance

Anissa Tonberg	Epilepsy Scotland (Chair)
Ian Williams	Quarriers (Vice Chair)
Norma Crawford	Quarriers
Scott Johnstone	Lanarkshire Epilepsy
John Bruce	Individual
Shirley Maxwell	Epilepsy Connections
Anna de Vries	Epilepsy Connections
Chris Jeans	SUDEP Action
Phil Robinson	Lanarkshire Epilepsy
Paul Gillon	Veriton Pharma
Rona Jonson	Epilepsy Scotland

Apologies

Annette Parker	Sense Scotland
Helen MacDonald	Lanarkshire Epilepsy

1. Welcome and apologies

AT welcomed everyone to the meeting and shared apologies. Having at least 6 different organisations present, the meeting was quorate.

2. Minutes of meeting held on 29 July 2020

The minutes were reviewed and were agreed as accurate. AT had circulated a shorter version of the minutes of the meeting held on 29 April 2020 for the website which were agreed as accurate. Going forward, brief minutes will be produced directly for the website.

3. Matters arising

- AT is stepping down as Chair for 12 months on 23 November to undertake a secondment. It was agreed that IW will remain as Vice Chair, and that RJ (who is acting up for AT at Epilepsy Scotland) will become Chair for the next 12 months. This will help to ensure continuity and support the smooth running of the Consortium.
- AT informed that the Scottish Medical Consortium has now finished their reviewing process; the drug Epidyolex is now approved for use in Scotland as an add-on therapy for young people under the age of 18 who have Dravet Syndrome or Lennox Gastaut Syndrome.
- NC forwarded the charges of alarms as outlined in the previous minutes.

4. Member Updates

Member organisations each gave an update on current work and how they are continuing to adapt to operating during the pandemic.

There were two action points stemming from this:

- AT to circulate eligibility criteria for epilepsy alarm vouchers.
- PG to circulate the information on the Veriton training app once it has been launched.

5. Parliamentary and Party Presentation

AT noted that traffic remains reduced due to the pandemic. Following a debate regarding the Cumberledge Review and the anti-epilepsy drug sodium valproate, there is to be a new Patient Safety Commissioner in Scotland. RJ is part of a group looking at this, which also includes individuals representing pelvic mesh implants and primodos. Once it is clear what the Commissioner remit will look like, there will be a Scottish Government consultation which the Consortium may wish to respond to.

CPG Update – RJ informed that the first virtual CPG via Zoom took place successfully at the beginning of October with 35 people attending. Some attendees fed back that they had preferred not having to travel to attend. This CPG meeting featured a speaker from the Scottish Learning Disability Observatory, presenting a study on mortality of children and young people with learning disabilities in Scotland.

The next CPG will take place on 9 December. This will be a joint meeting with the Multiple Sclerosis Society and will focus on social security. Time of the event and speakers are to be confirmed. The following meeting in February will focus on a video sharing service for patients that allows them to share videos of their seizures with their neurologist. The CPG will be disbanded just ahead of the Scottish elections in May. MSPs will be engaged ahead of the election to build a relationship and re-establish the group for September, when the next AGM will take place.

6. Identifying workstreams and priorities for action

AT asked present members to consider what other projects can be identified for the next 12 months. The priorities agreed upon are:

- **CPG Events**
Continuing to organise the CPG on epilepsy. Meetings are currently in hand for December and February. The CPG will then be required to pause until it is re-registered in September 2021, due to the Scottish Parliament election in May.
- **Consultation Response**
Undertaking a consultation response to the Scottish Government's consultation on the role of the Patient Safety Commissioner.
- **Qualitative Research**
Planning and commissioning a piece of qualitative research on an epilepsy-related topic. The intention is to generate some evidence on an issue, which in turn can generate media attention and drive some campaigning/lobbying work.
- **PIP assessments**
Continuing to lobby DWP/HMCTS about social security PIP assessments and tribunals, as appropriate.

Other opportunities were also discussed, such as the SNP party conference in April 2021, where charities can book a virtual exhibition booth (£2000 plus VAT). However, it was agreed that it would be helpful to gather feedback from organisations planning to attend a similar conference in November to find out how the experience was and whether it would be beneficial. Further, the next round of funding for the Neurological Framework will open and members might wish to come together to consider projects. It was also noted that Brexit is approaching, and that attention should be paid to the anticipated impact on people with epilepsy e.g. supply of medication. RJ is currently waiting in feedback regarding the stock of medication and how much of this was used for COVID-19.

Action: AT to circulate bullet points summarising the above decisions. RJ and IW to look at forming form a working party regarding commissioning research.

7. **Financial Report** (circulated with agenda)

AT reported there has not been much movement. The current financial resources amount to around £4,500. Notably, £250 were received from UCB for their subscription to the Consortium. For the last physical CPG held in February, £160 catering costs were paid in July. There is no other planned expenditure and no CPG related costs until September 2021. However it was agreed to ask Engage to invoice members for 2020/21 subscriptions, rather than have a 'payment holiday', to ensure there are sufficient funds to commission research in 2021 and to support the costs of the CPG if/when it reverts to being at the Scottish Parliament. It was agreed that the Consortium would pay £200 to Epilepsy Connections as a nominal fee/donation towards the provision of admin support. Historically, this appears to be the amount given to the member organisation providing administration to the ECS, as a donation to help cover staff time etc. Members felt that this was an appropriate action and use of funds. Regarding the Aged Debtors Report, it was decided to write off LivaNova and the Sense Membership subscription.

Action: AT to ask Engage to issue subscription invoices. AT to follow up with Engage about Aged Debtors.

8. **AOCB**

- **Consortium Membership Options**

There are currently several options and it was agreed that it would be beneficial to scale this down - specifically by removing the Associate Membership option and only having Individual and Organisational membership options.

- **News article**

A recent newspaper article featured the case of a child with rare complex of epilepsy and a communication breakdown with the consultant. There is not enough information available to comment on the case.

- **Adult Social Care Review**

The Alliance has taken the lead on reviewing Adult Social Care, specifically for people with neurological conditions and carers. SM enquired if organisations are intending to respond individually to the call for feedback. The review is looking at problems people are experiencing with social care and is to be completed by January. Epilepsy Connections attended one of the recent events which provided useful information, however, numbers of service users who have care packages are low.

Action: Rhona Figures from Epilepsy Connections to make initial contact with RJ.

- **PIP assessments**

A number of issues were raised about telephone PIP assessments, including client distress, lack of attention paid to medical evidence and questions unrelated to the person's condition. For professionals, it is difficult to effectively support individuals on the phone and the tribunal finds it difficult to gauge client distress during the call. The DWP are beginning to use some video-based assessments. It was agreed to feed back to the DWP on the user experience

9. **Date of Next Meeting**

Wednesday 27 January, 10.30am via Zoom