

Minutes of Epilepsy Consortium Meeting held on 29 January 2020
at The William Quarrier Scottish Epilepsy Centre

Attendance

Anissa Tonberg	Epilepsy Scotland (Chair)
Ian Williams	Quarriers (Vice Chair)
Scott Johnstone	Epilepsy Lanarkshire
Chris Jeans	SUDEP Action
John Bruce	Individual
Shirley Maxwell	Epilepsy Connections
Anna de Vries	Epilepsy Connections
John Thomson	Eisai
Paul Gillon	Veriton Pharma
Alison Corp	Epilepsy Nursing Consultant/Veriton Pharma

Apologies

Ian Forbes	UCB
Helen MacDonald	Epilepsy Lanarkshire

1. Welcome and apologies

AT welcomed everyone to the meeting and introduced AC and AdV to the Consortium. Apologies were read out.

2. Minutes of meeting held on 3 July 2019

The minutes were reviewed and were agreed as accurate.

3. Matters arising

These are covered in the agenda.

4. Financial Report

AT circulated the financial report and informed of issues with receiving finance reports in time despite repeated follow-ups and suggested that freelance support might be needed. The balance as of 31st December is just over £5,000. AT informed that £292 for the website and £240 for the CPG are about to come out of the account, leaving just under £5,000. Generally, present members were content with the financial report.

5. Parliamentary and Party Presentation

AT reported on recent events.

CPG Update – Dr Craig Heath presented at the last CPG meeting on 7th November. Alasdair Allan MSP (Convener of the CPG on Epilepsy) sent a letter asking the Government to support the database for epilepsy patients discussed at the previous CPG meeting.

It was noted that SIGN has still not released the paediatric guidelines, these are now expected in the summer.

AT noted that clinicians in Scotland are unable to take part in the Epilepsy12 audit which looks at the care children are receiving in the 12 months after epilepsy diagnosis. It involves 12 measurements and is undertaken UK wide, but currently has no funding to be carried out in Scotland. There has been back and forth between SPEN and the Scottish Government and AT noted that there seems to be a political dimension to this. AT informed that the government was approached about this before and granted the funding last time so it might be possible to get this again. AT and team are drafting a letter for the minister again and suggested that the CPG could be a good channel for getting access to the needed funding.

The next CPG meeting is on 27th February and will be about residential care provision which may be an emotive topic. AT is hoping for a debate that will inform the conversation in this area.

More CPG topics for this year are needed. In September it is planned to have a session from the Learning Disabilities Observatory, on epilepsy deaths data. This can be moved to an earlier date if needed. SJ suggested epilepsy and mental health. Employment and social security were also identified as a potential topics.

Action: AT to come back to other members about GPC topics.

6. ECS Website

JT informed that he is under a strict contract that does not allow for him to generate or suggest content for the website or to follow-up with people. He requires specific instructions and these must be received via AT. The website itself might benefit from a new look and some touch-ups. When content is uploaded it receives clicks and it was therefore suggested that members of the Consortium can send updates on their own organisations' activities to be uploaded on the website.

Action: AT will call AdV to pass on guidance on summarising minutes for the website. Also will meet with JT to discuss website 'spring clean'.

7. Membership

Annette Parker from Sense Scotland applied for an organisational membership. AT proposed to accept, JT seconded, and those present unanimously agreed. It could not be established whether the previous new member Ian Campbell had paid the membership fee on the bank statement from 31 December 2019. The question of getting involved in more active recruitment was raised, as many epilepsy training providers are not linked in with any epilepsy organisations.

Action: AT will check with Engage whether the membership fee was received.

8. Neurological Action Plan

Rona Johnson attended the release event of the Neurological Action Plan.

Epilepsy Scotland will attend a meeting in next month with 2 clinicians, civil servants, IT for GGC and a pharmaceutical representative to talk about the potential roll out of

a national epilepsy database. AT noted that this does not seem to require many resources but will need a champion in each health board.

AT encouraged all to look at the Framework's 17 commitments set over the next few years. Three new neurological leads need to be recruited, a process which is not outlined clearly as of yet. AT noted that £4.5 million of funding is allocated for 5 years. The funding is intended for services that work towards delivering the commitments but the process is currently not very clear. The Action Plan is reasonably generic and there are priorities for initial actions. The plan yet needs to be linked in with epilepsy and include indicators of epilepsy specific measurements.

Action:

AT asked all to think about their own services in terms of how they might be helping to deliver on the framework's commitments.

9. Updates

- Neurological Alliance of Scotland
Covered under item 8.
- Activities of member organisations/sharing intel

The paediatric nurse in Lanarkshire is retiring, the adult nurse retired last year and there has been no replacement. Two nurses are needed in the area and the post has been advertised for a while unsuccessfully. This is problematic and it would be beneficial to put pressure on the Health Board to address this. It was agreed that it would help to write to the board and present some specific cases of poor care.

10. AOCB

- Work on Protocol for Rescue Medication
AC, retired Epilepsy Specialist Nurse and learning and disability specialist, spoke about her work with Veriton Pharma on a protocol that aims to facilitate how the medication goes from the provider via the prescription to the patient. The prescriber needs to provide clear information about medication to patient. SIGN advises the use of a protocol to make this safe. The protocol will be a generic template that needs to be filled in individually for each patient to make it specific. Guidance on how to complete this will be available online and via an app. A completed example protocol will also be available for guidance. There is a need to implement this, especially for adults with learning disabilities or those who do not have a specialist available. AC is seeking feedback especially from those who provide epilepsy training. AC also advised that herself and Sally Ann Remnant another ESN are running a consultancy service. AC asked to come along to ESC meetings every now and then and the present members agreed as long as it is in a non-promotional capacity.
- Consortium Events (to be organised)
PG suggested to hold a public facing, promotional Consortium media event. AT noted that a topic specific campaign might give more media attention. It was further discussed to run a positive employers event to address the issue of many people with epilepsy not being in employment. It was proposed to hold a face to face, drop in event with MSPs around National Epilepsy Week in May, similar to an event held by Epilepsy Connections in the past. It would be useful to tie any event in with the

neurological action plan if possible. AT offered to help with this and suggested to form a small subgroup to aid with organisation.

11. Date of Next Meeting

Wednesday 29 April, 10.30am at William Quarrier Scottish Epilepsy Centre