

## Summary of minutes of Epilepsy Consortium Meeting held on 17 October 2018

### @ the William Quarrier Scottish Epilepsy Centre

#### Attendance

Sam Whitmore	Epilepsy Connections (Chair)
Anissa Tonberg	Epilepsy Scotland (Vice Chair)
Elaine Blackley	Quarriers (Secretary)
John Thomson	NHS Lanarkshire
Phil Robinson	Lanarkshire Epilepsy Support Group
Helen MacDonald	Lanarkshire Epilepsy Support Group
John Bruce	Individual
Kate Trenam	UCB
Gerard Gahagan	Quarriers (SEC)
Norma Crawford	Quarriers Fieldwork Services

#### Apologies

Shirley Maxwell	Epilepsy Connections
Chris Jeans	SUDEP Action
Eugene Chizooma	Eisai
Ian Forbes	UCB
Lorraine Jackson	Quarriers (SEC)
Eugene Chizooma	Eisai
Paul Gillon	Veriton Pharma

#### 1. Welcome, introduction and apologies

Sam welcomed everyone to the meeting and welcomed Norma Crawford to the group. Apologies were read out.

#### 2. Minutes of meeting held on 4 July 2018

The minutes were reviewed and agreed as accurate.

#### 3. Matters arising

These are covered in the agenda.

#### 4. Financial Report

Income and Expenditure for period along with the Aged Debt report were circulated to the group.

#### 5. Parliamentary and Party Presentation

Anissa reported on recent events.

CPG update – attendees have increased over the past four CPG meetings. Last year there had been on average 20-30 people in attendance however at the first CPG of 2018 36 people attended, 46 attended the second, 56 attended in April and a

similar number in September. More clinical community accounts for these attendees. AT the last CPG meeting in September the Minister for Public Health advised the Neurological Action Plan was being released for consultation soon. Stephanie Fraser, CEO of Bobath gave an overview of the work being carried out. This was a joint meeting with the MS Society and seemed to work well. It was therefore agreed that they will continue to hold three meetings and one joint meeting each year. Alongside the Neurological Action Plan, new general standards on neurology have been drafted and released for a three month consultation period. Neurological Alliance and Health & Social Care Alliance will hold an event in November in relation to this.

## **6. SEC – a nationally designated service**

GG spoke to the group. Advised the ECS members were fundamental to the support of the centre. Scottish Government is behind the development and support of the service. The centre is recognised as a flagship neurological service. GG advised the Neurological Action Plan is due to be launched.

## **7. 5<sup>th</sup> Anniversary/ECS Conference**

SW updated the group with registration information for the forthcoming LD conference. It was agreed that all four workshops will run perhaps once or twice and have a designated time slot. Two organisations will facilitate each. Each workshop will run for approximately 45mins to an hour and will end in action points and participative discussion. It was also discussed that there should be GDPR evaluation forms to allow expressed consent for pictures to be taken on the day. Overall summarised action points of the day will be linked via the website. Information stalls for all ECS members will be free on the day and will be in the room.

## **8. Website**

AT advised that she has submitted her bio for publishing. GG still to send.

**Action:** GG to complete.

## **9. General Data Protection Regulation (GDPR)**

A discussion took place as to whether each individual had to complete a GDPR compliance form or whether it was merely one for each company. It was agreed that there was a requirement from each organisation only.

## **10. Updates**

### **1. Neurological Alliance of Scotland**

General standards for neurological conditions out for public consultation. Engagement feedback consultation event on 12<sup>th</sup> November 2018 for those who have a neurological condition, group discussions and looking at standards. It has been a very active year for the Alliance and relationship with Scottish Government is very strong. Epilepsy is a key issue to be placed on Scottish Access Collaborative to reduce times on NHS. AT advised that so much has happened this year whilst GG has been Chair.

2. National Advisory Committee for Neurological Conditions (NACNC)

Should have been launched on 16<sup>th</sup> October however this was pushed back to November. Scottish Government have not had to deal with National Action Plan before and “support a critical role of 3<sup>rd</sup> party organisation”

3. Activities of member organisations/sharing intel

- GG spoke to the group and advised that the JEC has now ceased/dissolved.
- GG informed the group that there will be an Epilepsy and LD launch which is awaiting Scottish Government sign-off. This is in regards to improving the care in people across Scotland and involved the LD network.
- AT spoke to the group and advised that SIGN’s paediatric guidelines are near draft stage. The national meeting will be held on 8<sup>th</sup> November in Stirling. Chapter on transition is key priority and places will be able to be booked via Eventbrite.

**11. AOCB**

Secretary to the ECS position is now coming to the end of the contract however EB has agreed to continue for one further year to keep in alignment with posts of SW and AT. Group thanked EB for continuing.

**12. Date of Next Meetings**

2019 meeting dates have been scheduled for the following dates:

**23<sup>rd</sup> January 2019 @ 10.30am (Venue SEC)**

**10<sup>th</sup> April 2019 @ 10.30am (Venue SEC)**

**3<sup>rd</sup> July 2019 @ 10.30am (Venue SEC)**

**23<sup>rd</sup> October 2019 @ 10.30am (Venue SEC)**

Everyone was reminded that video link was available or NHS Attend Anywhere.