**Minutes of Epilepsy Consortium Meeting held on 23 October 2019**

**at The William Quarrier Scottish Epilepsy Centre**

**Attendance**

Sam Whitmore Health Scotland (Chair)

Anissa Tonberg Epilepsy Scotland (Vice Chair)

Norma Crawford Quarriers

Scott Johnstone Epilepsy Lanarkshire

Ian Forbes UCB

Chris Jeans SUDEP Action

Emily Ord Eisai

Lorraine Jackson Quarriers

Phil Robinson Epilepsy Lanarkshire

Ian Williams Quarriers

**Apologies**

John Bruce Individual

Paul Gillon Veriton Pharma
Shirley Maxwell Epilepsy Connections
John Thomson Eisai

**1. Welcome, introduction and apologies**

Sam welcomed everyone to the meeting. 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**

Discussed and approved.

SW asked members about whether they would like to continue to chase people for their event fees for the conference in 2018 or write the debt off. Members agreed to write off all debt relating to the event held in 2018.

**5. Parliamentary and Party Presentation** Anissa reported on recent events.

**CPG Update –** AT noted the last meeting was at the end of September. Dr Ian Morrison and Dr Craig Heath talked about a database for epilepsy patients which has already been established in NHS GGC and NHS Tayside. The database will include a dashboard which will flag clinicians about any events that happen to their patients e.g. if they are admitted to hospital, die, are not taking their medication as prescribed or fall pregnant.

The main push behind their talk is about how this can be nationally rolled out. AT said there has been some Scottish Government interest, especially on the research side of things. AT noted that Epilepsy Scotland is writing a letter alongside Alasdair Allan MSP (Convener of the CPG on Epilepsy) asking the Government to support the database. Epilepsy Scotland will also write to all the health boards to ask them to implement the database.

There are some IT issues, very labour intensive to populate the database. AT believes there may be some money attached to the launch of the Neurological Action Plan, to help support the implementation of the database.

Next CPG meeting is 7th November and will be about the new SIGN Guidelines on diagnosing and managing children with epilepsy.

In January the meeting proposed is out of area placements. It is about people who have complex needs who need residential support but cannot be accommodated in their area and have to be placed elsewhere, often very far from home.

PIP petition update – reached 5,000 signatures. After 10,000 the government will respond.

**6. Website**

Website usually managed by JT, who was not in attendance at the meeting. SW suggested that once the new office bearers are elected the website could do with a spring clean. Said the website is not highlighting everything that the Consortium does, could be better.

 ***Action:*** EO will put a link to the petition on the Consortium website.

**7. Updates**

* Neurological Alliance of Scotland

AT said the focus of NAS will be on the Neurological Action Plan and the General Standards. The Government view NAS as a “go to” umbrella organisation.

* National Advisory Committee for Neurological Conditions (NACNC)

AT said they are scaling down the committee, will be focussing on the Neurological Action Plan.

* Activities of member organisations/sharing intel

CJ noted that 23rd October is SUDEP Action day. It is an international awareness day which raises awareness about epilepsy safety. They are launching a SUDEP safety checklist in Australia, widely used internationally.

AT gave a Brexit update; a cross charity letter went to Government after the publication of Yellowhammer. After Epilepsy Scotland met with the Scottish Government, AT believes they are doing everything they can to mitigate issues with medications. AT noted Epilepsy Society’s work on publishing medication shortages and detailing what to do if someone experiences a shortage.

***Action:*** AT will send round the link to Epilepsy Society’s work.

IF noted that the epilepsy database will try to track medication adherence through prescription tracking, aims to have it up and running next year. UCB will also look at supporting learning disability nurses to upskill their knowledge about epilepsy.

HJ said that Irish colleagues came over to investigate avenues in building an Irish Epilepsy Centre.

IW provided an update on Quarriers’ fieldwork service. Unfortunately they have had to withdraw their epilepsy fieldwork service in Tayside. Looking towards more sustainable funding which will hopefully be supported by research they have carried out.

**8. Election Office Bearers**

SW confirmed following on from nominations the new office bearers are as follows:

Chair: Anissa Tonberg, Epilepsy Scotland

Vice Chair: Ian Williams, Quarriers

Treasurer: Carry on with Engage, at present

Secretary: Epilepsy Connections

SW noted he enjoyed his time as Chair and thanked members for their support.

**9. AOCB**

AT and members thanked SW for all of his efforts in his role as chair. AT particularly thanked SW for continuing as chair despite moving sectors.

SW noted a new member, Ian Campbell.

***Action***: SW will send over his details to the new chair.

**10. Date of Next Meeting**

 **TBC (Venue SEC)**

 SW thanked members for attending the meeting.