

# Minutes of Epilepsy Consortium Meeting held on 29 July 2020

## Via Zoom

### Attendance

Anissa Tonberg	Epilepsy Scotland (Chair)
Ian Williams	Quarriers (Vice Chair)
Norma Crawford	Quarriers
Annette Parker	Sense Scotland
Scott Johnstone	Lanarkshire Epilepsy
Helen MacDonald	Lanarkshire Epilepsy
John Bruce	Individual
Shirley Maxwell	Epilepsy Connections
Anna de Vries	Epilepsy Connections

### Apologies

Chris Jeans	SUDEP Action
Phil Robinson	Lanarkshire Epilepsy
John Thomson	Eisai
Rona Jonson	Epilepsy Scotland

### 1. Welcome and apologies

AT welcomed everyone to the meeting and shared apologies.

### 2. Minutes of meeting held on 29 April 2020

The minutes were reviewed and were agreed as accurate. AT noted that the minutes are normally published on the website. Due to the sensitive nature of some of the information, it was proposed to create a basic summary of the minutes for publication. Present members agreed. It was further agreed to produce briefer minutes in the future that can be published on the website immediately.

**Action:** AT to prepare a shorter version of the minutes of meeting held on 29 April 2020 for the website.

### 3. Matters arising

- AT informed that the meeting with the Scottish Medical Consortium regarding the drug Epidyolex was undertaken virtually but that restrictions prevent her or other attendees to share what was discussed. The SMC Committee meets in August and their decision will be published in early September. Being part of the meeting was a highly positive and encouraging experience.

### 4. Member Updates

- Epilepsy Scotland  
AT informed that Epilepsy Scotland is preparing to return to some face-to-face interaction in September. Donated laptops/ipads are being provided to children with epilepsy to help support them in their learning. There had been a drop in PIP applications in the beginning of lockdown which has now increased again. One of their welfare officers retired and while it is a challenge to recruit right now, this is currently being investigated.

- Quarriers  
Scottish Epilepsy Centre:  
IW advised that the centre re-opened 3 weeks ago at a reduced capacity. Individuals have tolerated self-isolation, are adhering to social distancing and are wearing PPE. COVID-19 testing is in place for new arrivals. Feedback suggested that people coming to the centre felt safe. There is still a significant number of people waiting to come for their first visit. The capacity is continuously being reviewed to increase this as soon as it is safe to do so. After a cohort leaves, the centre is closed and deep-cleaned before opening for the next cohort.

Epilepsy Fieldwork Service:

NC informed that fieldworkers are mainly working from home but have been dropping off well-being packs. Training is delivered online, and face-to-face interaction might be a possibility next month. Soon a survey will be carried out to see how individuals feel they have been supported during lockdown.

- Lanarkshire Epilepsy  
SJ advised that walking groups and individual walks are being set-up. A lending library of equipment (e.g. epilepsy alarms) is now in place to allow individuals to test if the equipment works for them. Due to funding restrictions, this only applies to the Lanarkshire area. NHS Lanarkshire is unable to refer individuals to Lanarkshire Epilepsy for alarms as there is little evidence for efficacy, however the local authority could be approached regarding this.
- Epilepsy Connections  
SM reported that staff are still working from home but that returning to face-to-face services is currently being considered. It is expected that aspects of services will remain remote. Services are busy, and the allotment project is back running under certain constraints. Soon, outside groups will be launched to allow people to meet safely in person. Everyone at Epilepsy Connections is getting ready for the next normal, whatever this will look like.
- SENSE Scotland  
AP informed that, as in other organisations, staff continues to work from home. Training is provided online and plans are drafted regarding room expansions to bring people into services at a safe distance. AP also noted that Headway is offering activities for individuals.

## 5. Financial Report (circulated with agenda)

AT reported there has not been much activity. The invoice on income expenditure for the last CPG was paid in July. ECS members are usually invoiced for their membership over summer but this has not been issued yet. Epilepsy Connections is due some recompense for offered admin support.

**Action:** AT to investigate how much recompense Epilepsy Connections will receive and when membership invoices will be issued.

## 6. Parliamentary and Party Presentation

AT reported on recent events and noted that traffic has been reduced due to the pandemic. Data was released about the number of COVID-19 deaths in people with learning disabilities in England and it is unclear if this is reflected in Scotland. This is currently being investigated. AT invited present Consortium members to suggest issues that require lobbying and political action. The Cumberledge Review and the

anti-epilepsy drug sodium valproate was suggested to be pursued. A discussion arose about providing an online learning day e.g. for social care professionals, educational staff, school children and parents. Epilepsy organisations are involved in working with schools, but the Consortium might be able to support this through putting pressure on the educational body or providing online training. Concerns were voiced about how receptive individual schools and education departments are going to be to matters not directly relating to the curriculum. This might be a topic to revisit at the start of 2021.

**Action:** AT to email members to gather interest in joining a working group re sodium valproate.

**CPG Update** – AT informed that the Consortium event aiming to generate conversation with MSPs booked for May was rescheduled for 1<sup>st</sup> October. However, 1<sup>st</sup> October seems ambitious for a face-to-face meeting due to unpredictable factors. As another CPG meeting and the AGM need to take place and was planned for end of September/beginning of October, this could be held before/after or instead of the Consortium event. Further, present members agreed that it is more realistic to plan an online event which will require additional admin support for monitoring the meeting and admitting attendees. This CPG meeting will be discussing the mortality of children and young people with disabilities in collaboration with the Learning Disability Observatory Glasgow. This might generate awareness of needed political action for improvement.

**Action:** AT to gather information from those who have run an online CPG event.

## 7. Health Boards/Services

RJ wrote to Health Boards asking about access to tests and specialists, contact with neurological services and plans. It was asked to prioritise returning epilepsy staff to their services and what is being done about that. The responses mainly outlined that most nurses are back in their services but that there is no face-to-face contact. NHS Lanarkshire responded on 2<sup>nd</sup> June and acknowledge that the nursing post was not filled during the 2019 recruitment and that there was hopes a recently retired doctor would return. The nursing post has been re-advertised. A neurologist is currently being recruited in Glasgow which will support Lanarkshire. RJ will write for an update once the recruitment has concluded. NHS Highland was also asked about their nursing post. There has been no response yet which will be followed-up.

## 8. ECS Website

The last set of minutes was uploaded to the website. There are a few things AT needs to send to JT but, because there is not much activity with the Consortium, little needs to be done on the website.

## 9. Neurological Support and Care Framework

SM informed that funding in relation to the framework has been released. Applications for round 1 funding are open now until September. Projects applying for funding need to relate to the priorities outlined in the framework and £500 000 across Scotland are available in total for this year for all neurological conditions. The funding involves £4.5 million over 3 years. The Neurological Alliance is hosting a workshop on 17<sup>th</sup> August to look at structuring organisations' bids. The workshop is open to NHS boards, health and social care partners and non-profit organisations.

**Actions:** AT to circulate details for the session. SM to circulate link to find information for funding and application form.

## 10. AOCB

- **Tele-care subscriptions**  
NC informed about differences in subscription prices and rates for number of devices for Tele-care services in different areas. In some cases, phone lines need to be put in which comes at an additional cost and many people do not use call/seizure/bed alarms due to the high costs involved. This presents a risk to individuals and affects people with epilepsy as well as others who need call alerts. There is potentially a case to be made with local authorities.

**Action:** NC to pass on the rates she knows about.

- **Telephone tribunals**  
Experiences with social security telephone tribunals were mixed. While backlog is being cleared as much as possible, supporting individuals during phone tribunals has been challenging for representatives. Tribunals are now starting to return to face-to-face but there will be fewer initially.
- **Remote health consultations**  
Personal experiences of NHS health phone consultations highlighted potential issues with the format. The Scottish Government is currently running a consultation on patient experiences of virtual consultations. It might be possible to submit experiences either from the Consortium or as an individual. Also, the Neurological Alliance might be working on an evaluation of virtual means and remote consultations which might present an opportunity for providing feedback.

**Action:** AT to investigate both options for providing feedback on virtual/phone consultations.

- **Seizure alarm vouchers**  
Epilepsy Scotland has received vouchers for epilepsy alarms. Once criteria for how the process will work are in place, individuals will be able to self-refer rather than being referred through the NHS.

**Action:** AT to write protocol for how people can apply for them.

- **Benefits social security bill**  
This summer a bill is being drafted for people who still have capacity but would prefer having an appointee. While this has been framed to be intended for those with a terminal illness, it might include those with a mild learning disability or children in transition ages.

## 11. **Date of Next Meeting**

Wednesday 28 October, 10.30am via Zoom