

Epilepsy Consortium Scotland (ECS) Secretariat

Anissa Tonberg: 48 Govan Road, Glasgow G51 1JL

Tel: 0141 427 4911

atonberg@epilepsyscotland.org.uk

Note of Meeting – Cross- Party Group on Epilepsy, 27th April 2017

In Attendance:

Dr James Anderson, Quarriers & Division of Neuropsychology Scotland	Carsten Mandt, NHS National Services Scotland
Mary Antczak, Epilepsy Connections Peoples' Forum	Shirley Maxwell, Epilepsy Connections
Guy Armstrong, UCB Pharma	Darren McCarthy, LivaNova
Dr Jean Barclay, Observer	Dr Ailsa McLelland, NHS Lothian
John Bruce, Epilepsy Connections	Hilary Mounfield, Scottish Epilepsy Centre
Aileen Campbell MSP, Minister for Public Health and Sport	Gil Paterson MSP
Rich Curtis, LivaNova	Brian Rocks, West Dunbartonshire Support Group
Bridie Fordham, West Dunbartonshire Support Group	Dr Aline Russell, Scottish Epilepsy Centre
Tom Fordham, West Dunbartonshire Support Group	Dr Eleonora Saturno, Consultant Neurologist
Kenneth Gibson MSP	Michelle Small, NHS Lothian
Paul Gillon, Special Products Ltd	Emma Swift, Parliamentary Researcher to Lewis Macdonald MSP
John Heaney, West Dunbartonshire Support Group	Sharon Thinn, NHS Fife
Gillian Horsburgh, NHS Greater Glasgow & Clyde	John Thomson, Eisai
Jeffrey Hughes, Observer	Anissa Tonberg, Epilepsy Scotland
Chris Jeans, SUDEP Action Scotland	Colin Urquhart, Scottish Government
Sylvia Lawrie, Observer	Lesslie Young, Epilepsy Scotland
Dr Veronica Leach	

Apologies:

George Adam MSP	Fiona Hughes, Epilepsy Specialist Nurse, NHS Fife
Jane Anderson, Epilepsy Specialist Nurse, NHS Fife	Jennifer Irvine, NHS Lanarkshire
Jeremy Balfour MSP	Helen MacDonald, Lanarkshire Epilepsy Support Group
Matt Barclay, Director of Operations, Community Pharmacy Scotland	Lewis Macdonald MSP
Celia Brand, NHS Lothian	Lorraine Mackenzie, Observer
Dr Ruth Brotherstone, NHS Lothian	Peter Martin, Observer
Susanne Cameron-Nielsen, Royal Pharmaceutical Society	Dr Pamela Martis, NHS Lothian
Donald Cameron MSP	Ann Maxwell, Muir Maxwell Trust
Jane Cassidy, Observer	Susan Riddell, Epilepsy Specialist Nurse, NHS Fife
Alex Cole-Hamilton MSP	Dr Phil Robinson, Epilepsy Consortium Scotland
James Dornan MSP	Anas Sarwar MSP
Neil Findlay MSP	Dr Jane Stuart, NHS Lothian
Andrena Hughes, Observer	

1. Convener Kenneth Gibson MSP welcomed attendees to the meeting. He then welcomed guest speaker Aileen Campbell MSP, Minister for Public Health and Sport, to talk about government policy and epilepsy services in Scotland.
2. Aileen Campbell (AC) thanked Kenneth Gibson for having invited her to speak to the group. She outlined the value of Cross Party Groups in enabling MSPs to work alongside people with experience of conditions in order to advance policy areas and awareness. She said that cross-sector collaboration was important in helping to improve services for people living with epilepsy. The Minister then went on to make the following points in her speech:

- The Scottish Government (SG) has a long and close working relationship with charities such as Epilepsy Scotland and Quarriers and shares the vision that all people with epilepsy be treated fairly and be able to reach their own potential. The government is committed to ensuring all people with epilepsy in Scotland are able to access the best support and health services which are safe, effective and have the patient at the centre of their care.
- When the former Minister for Public Health Jamie Hepburn spoke at the CPG last year, he was keen that the government work with the third sector. Since then officials have met with Epilepsy Scotland and the Epilepsy Consortium Scotland. Following this, the SG has provided funding to Epilepsy Scotland to support a benefits advice service specifically designed for people with epilepsy, helping them to claim disability benefits and reduce the stress and anxiety associated with claiming and assessment which may impact their epilepsy. The service will be up and running later this year.
- The SG is about to take on new social security powers and has committed to building a fairer system around the needs of the person with the disability. Wherever possible assessments will be paper based rather than face to face, to avoid the revolving door of assessment and the stress and anxiety associated with this. The new system will put equality and respect at the heart. The Minister for Social security has organised expert panels for the summer and AC urges attendees to become involved with this if they are able. AC has heard of the difficulties experienced by people with a wide range of conditions, when claiming disability benefit. We need something better in Scotland which takes account of the lived experience of people with the condition and those who are involved in their care, to deliver something better.
- In terms of national work – the NACNC are looking at models of care which represent the improvements we would like to see, such as
 - Person-centred care and support with care delivered by skilled nurses, therapists, doctors and care teams
 - Better access to specialist services and opportunities to participate in research into new treatments
- There are representatives from the epilepsy community on the committee, and there is a further epilepsy subgroup aimed at making life better for people who live with the condition. AC has asked the committee to report back to her and she looks forward to hearing their recommendation on how the SG can take forward policy at that national level for neurological conditions such as epilepsy.
- AC said she hoped this gave a flavour of the work which is ongoing across the SG but also an illustration, following Jamie Hepburn's presentation about the importance of closer working relationships, of examples where they have made progress and funded projects with third sector partners. She felt the only way to go on was to continue to work together, in partnership, and by coming to speak at meetings like this in order to make the changes to policy and generate improvements which everyone wishes to see.
- AC thanked the group for inviting her to speak

3. Kenneth Gibson MSP thanked the Minister for her presentation and invited questions from the attendees.

- Anissa Tonberg asked about access to epilepsy specialist nurses. Scotland has roughly half the number of epilepsy specialist nurses it needs and two health boards have no paediatric specialist nursing at all for epilepsy. What can the SG do to help support the increase of this kind of provision in Scotland? AC replied that getting the right kind of care for patients was important and that is why specialist nurses are critical, citing the recent increase in specialist staff for Multiple Sclerosis and Motor Neurone Disease. The SG will receive a report this summer evaluating the impact of extra specialist nursing funding in terms of delivering extra capacity and access for patients. That is recurring funding, so they will be looking at how to maximise the impact of it going forward. She commented that there

has been a small increase in epilepsy specialist nursing provision between September 2015 and September 2017.

- Dr Aline Russell asked about better access to diagnostics for epilepsy, in particular neurophysiology. She said the speciality is in dire straits and lacks staff, both consultants and physiologists, with vacancies around the country. She said this small specialty has a very significant role in securely diagnosing epilepsy and needs investment for training more physiologists, needs time to look at how to deliver the specialty in a different way to give Scotland better coverage – Edinburgh and Aberdeen currently have single handed locum consultants. There is at times a 50% national vacancy rate which makes it almost impossible to provide a timely specialist services for patients with epilepsy, concerning diagnosis. AC replied that this was a very important issue and that the SG has been in contact with NHS Lothian over the particular pressures they face there. She agreed that the SG has a leadership role in this problem and has brought together regional planners and hope to hold a meeting this summer with them and people with expertise in physiology. It is not a straightforward thing to fix and there will be a time-lag in training new staff. The SG hopes to drive this issue and have a clear plan with identifiable ways to make this situation better. AC's team will undertake to keep the CPG up to date with that.

- Dr Veronica Leach asked who the Minister planned to invite to the meeting in the summer to address this problem. AC invited Colin Urquhart, policy lead for neurological conditions, to comment on this. He explained that the SG had tried to progress this issue through the regional planners forum, however following limited progress the SG is taking more leadership role and plans to invite people who are involved in delivering the service, possibly chaired by chair of the NACNC, Dr Richard Davenport. He said they are happy to engage with any ideas over how to run it and who else to invite. Dr Leach felt it was important to engage with neurophysiologists working on the ground, particularly those who are in over-stretched areas. AC asked for the contact details of such individuals through Convenor Kenneth Gibson and the Secretariat.

- Dr James Anderson asked about Social security expert review panels. He said making arguments for 'unseen' symptoms such cognitive impairments was an ongoing challenge in supporting people with epilepsy claiming PIP and wondered if the expert panels have already been convened? AC replied that they begin in the summer, it is being coordinated by Jeane Freeman MSP, if he feels there is an issue about understanding peoples' cognitive problems, she would be pleased to hear about it.

- John Heaney felt that epilepsy welfare rights advisors should also be embedded within local authorities – he described difficulties in travelling for advice and the need for input locally, citing the difficulties experienced by members of his local support group. AC agreed that geography poses a big problem for people and that they need adequate support locally, though felt that bodies like Money Matters and third sector organisations support well in local areas. She commented that the Epilepsy Scotland post is also to enhance understanding in other bodies. Anissa Tonberg commented that the advisor will have a budget to travel and advise people at home, and would also train other benefits advisors in councils, CAB etc. in how to support claimants with epilepsy.

- Dr Ailsa McLellan highlighted fact that there are two areas in Scotland which have no paediatric epilepsy nursing provision and that this is a long standing issue which people

have tried to address locally through the health board, and nationally through the Scottish Paediatric Epilepsy Network. She asked, as a representative of paediatric neurology, what support this group can give as the issue keeps stalling? AC suggested this could be picked up by NACNC epilepsy subgroup and that it might be picked up by summer meeting on neurophysiology. AC said she will raise it with the chief nursing officer, who is preparing a report on how services have been enhanced through specialist nursing and to see if she has cognisance of that situation. AM said specialist nurses were a very important resource for children and families.

- Dr McLellan further said that the situation for neurophysiology NHS Lothian is critical, with long vacant posts, but that any support given from this group to support would be helpful as it is a critical procedure in epilepsy.

- Dr Eleanora Saturno stated that the neurophysiology situation is a complex problem, and asked if it would be worth opening the summer meeting to anyone who wants to attend to generate a complete picture: e.g. patient representatives, neurophysiologists, paediatric neurologists. AC replied that it was not that they don't want it to be open, but she is wary of making scope so wide that it limits progress. She said there needs to be strong input and balance and sufficient focus with right people around table. This will not be a one-off meeting – the SG will give thought to how sequence things and get right balance. Colin Urquhart added that they will likely write to CPG about the meeting.

The Convenor invited any final questions:

- Brian Rocks talked about his experience of assessment for Personal Independence Payment, the inconsistencies in decision-making and lack of knowledge about epilepsy as a condition. AC further discussed the upcoming changes to the social welfare system in Scotland. She said both she and the Convenor have constituents who visit having lost benefits and with severe problems in claiming what they are entitled to.

- Hillary Mounfield stated that she was involved in setting up the CPG when parliament opened and has never known such strength of feeling among medical professionals in the epilepsy world about the seriousness of the current situation concerning care. She urged the Minister to take it on board, that people were 'not just shouting for sake of it, but desperate to provide better care for patients'. AC said that she understood, that the SG is trying to take ownership of this and elevate it on a national basis and will continue to engage with the CPG.

- Anissa Tonberg raised the issue of poor mental health in children and young people with epilepsy, on behalf of Celia Brand, Epilepsy Specialist Nurse (ESN). She said that ESNs report struggling to refer young people with epilepsy to CAMHS, with frequently rejected referrals which effectively leave children in limbo. She asked how the SG can help this situation. AC mentioned the new mental health strategy, that the SG is working to get better idea of numbers of those needing help, and that there is the opportunity to stay in touch with the CPG regarding access to CAMHS etc. She further added that this relates to GIRFEC and the legal responsibilities around the health and welfare of Scotland's children.

- The Convenor thanked the Minister again and said it was most encouraging to hear her answers. He added that from CPG perspective we would like to invite her again this time next year and check in on what progress has been made over the year.

4. The Convenor then turned to business of the meeting, which he began by wishing Allana Parker, the recently retired Secretariat to the CPG, the best for the future and saying that she is sadly missed.

- The group checked minutes of the previous meeting for accuracy, which were approved. The Convenor reminded group members that they that can approach their own MSP, CPG member MSPs, the Convenor himself or the Secretariat with any issues. Also that MSPs can ask written parliamentary questions on any topic.

- Dr Ailsa McLellan commented about the rising prices of several epilepsy drugs. She noted that pricing issues continue, with clinicians having to reconsider prescribing high-cost drugs. The Convenor suggested having someone from the Scottish Medicines Consortium to talk to the group about how cost/benefit is assessed in licencing drugs for use in NHS Scotland.

- The Convenor updated the group on recent parliamentary motions and said that over 40 MSPs were involved in raising awareness of Purple Day, via dressing in purple and using social media etc.

- The Convenor is sponsoring an information stand in the garden Lobby during National Epilepsy Week in May. The theme will be improving the mental health of people with epilepsy. The Convenor reminded members to suggest topics for the coming year and that the Secretariat will ballot on these. The next meeting will be just after parliamentary recess, the Secretariat will advise the group once it is booked.

- The Convenor thanked everyone for contributions and wished members well for the summer before closing the meeting.