

Epilepsy Consortium Scotland (ECS) Secretariat

Anissa Tonberg: 48 Govan Road, Glasgow G51 1JL

Tel: 0141 427 4911

[atonberg@epilepsyscotland.org.uk](mailto:atonberg@epilepsyscotland.org.uk)

## Note of Meeting – Cross- Party Group on Epilepsy, 25<sup>th</sup> January 2018

### In Attendance:

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| Mary Antczak, Epilepsy Connections Peoples' Forum             | Yvonne Leavy, NHS Lothian                            |
| Eleanor Arthur, NHS Greater Glasgow & Clyde                   | Carsten Mandt, SPEN                                  |
| Jeremy Balfour MSP  | Dr Pamela Martis, NHS Lothian                        |
| Dr Jean Barclay   | Shirley Maxwell, Epilepsy Connections                |
| Celia Brand, NHS Lothian                                      | Barbara McCullough, Observer                         |
| John Bruce, Epilepsy Connections People's Forum               | Michael McCullough, Observer                         |
| Sharon Cairney, Epilepsy Connections Peoples' Forum           | Clare McDade, NHS Greater Glasgow & Clyde            |
| Dr Alastair Campbell, NHS Lothian                             | Alleson McNeill, NHS Lothian                         |
| Dianne Carroll, NHS Greater Glasgow & Clyde                   | Carol McNeil, Epilepsy Connections Peoples' Forum    |
| Eugene Chizooma, Eisai Ltd                                    | Rose Marie Parr, Scottish Government                 |
| Dr Chris Derry, NHS Lothian                                   | Ronnie Prentice, West Dunbartonshire Support Group   |
| Dr Susan Duncan, NHS Lothian                                  | Brian Rocks, West Dunbartonshire Support Group       |
| Yasmin Erginsoy, Communications Manager to Kenneth Gibson MSP | Dr Aline Russell, Quarriers Scottish Epilepsy Centre |
| Ian Forbes, UCB Pharma  | Claire Scott, Observer                               |
| Bridget Fordham, West Dunbartonshire Support Group            | Pauline Smith, NHS Tayside                           |
| Tam Fordham, West Dunbartonshire Support Group                | Dr Linda Stephen, NHS Greater Glasgow & Clyde        |
| Kenneth Gibson MSP  | Dr K Kamath Tallur                                   |
| Anne Gray, West Dunbartonshire Support Group                  | John Thomson, Eisai Ltd                              |
| Ann Greenall, NHS Fife  | Anissa Tonberg, Epilepsy Scotland (CPG Secretariat)  |
| Fiona Hughes, NHS Fife  | Sam Whitmore, Epilepsy Connections                   |
| Chris Jeans, SUDEP Action Scotland                            | Margaret Wilson, NHS Greater Glasgow & Clyde         |
| Barbora Jones, Epilepsy Connections                           | Lesslie Young, Epilepsy Scotland                     |
| Dr Corinne Love, Scottish Government                          | Susan Yule, NHS Greater Glasgow & Clyde              |

### Apologies:

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|---|---------------------------------|
| Declan Aherne, NHS Lothian                          | Ann Maxwell, Muir Maxwell Trust |
| Jane Anderson, NHS Fife                             | Dr Ailsa McLellan, NHS Lothian  |
| Dr Catherine Calderwood, CMO, Scottish Government   | Hilary Mounfield, Observer      |
| Jane Cassidy, Observer                              | Jillian Rose, Observer          |
| Alex Cole-Hamilton MSP                              | Katy Ruggeri, NHS Lothian       |
| Mary Fee MSP  | Anas Sarwar MSP                 |
| Neil Findlay MSP                                    | Eleonora Saturno, NHS Lothian   |
| Gerard Gahagan, Quarriers Scottish Epilepsy Centre  | Dr Jane Stuart, NHS Lothian     |
| Paul Gillon, Veriton                                | Sharon Thinn, NHS Lothian       |
| Andrena Hughes, Observer                            | David Torrance MSP              |
| Helen MacDonald, Lanarkshire Epilepsy Support Group | Annie Wells, MSP                |
| Lorraine MacKenzie, Observer                        | Bill Whittle, MSP               |
| Frances Maguire, NHS Lothian                        |                                 |

1. Convener Kenneth Gibson MSP welcomed attendees to the meeting.
2. He gave a short update: no changes to the circulated September 2017 draft note, it was approved.
  - There has been some positive success on the ongoing problem of access to EEG, VT and neurophysiology services for people with epilepsy around Scotland. Patients in NHS Lothian were experiencing an 18-month patient wait for video-telemetry due to the loss of

beds and staff resource. Following our CPG meetings on neurophysiology and dialogue with the Minister, plus the efforts of clinicians, NHS Lothian reopened the two VT beds in October, with additional nursing staff. They also awarded £32,000 to the neurophysiology department to purchase home VT equipment. The waiting list initially dropped from 18 months to 7 months, with further improvement anticipated when the service moves hospital in the coming months.

- Also thanks to the CPG, the Scottish Government held a national meeting in November with neurophysiologists from around the country to examine the wider issues and try to find solutions. The Minister for Public Health's office is due to circulate a note of the meeting and some suggestions about potential ways forward.
- Legislation has been adopted by the Scottish Parliament which will close the loophole allowing manufacturers of generic drugs to charge exorbitant prices for them.
- Kenneth Gibson MSP submitted a parliamentary motion congratulating Quarriers Scottish Epilepsy Centre on winning the prestigious Laing Buisson award for excellence in primary care and diagnostics. He also submitted three parliamentary questions – one about sodium valproate and preconceptual counselling for women with epilepsy; one concerning morbidity and mortality in pregnant women with epilepsy and the need for joined up care; and one about the lack of paediatric epilepsy specialist nursing in NHS Dumfries and Galloway. The Cabinet Secretary for Health has answered the first of these, and each of the answers will be circulated by the secretariat.
- Kenneth Gibson MSP has written to the Minister of Public Health on behalf of Epilepsy Scotland to ask about the future of Section 10 government funding.
- The CPG is aiming to secure a parliamentary debate relating to epilepsy during National Epilepsy Week in May, most likely regarding epilepsy and mental health.
- A site visit to the Scottish Epilepsy Centre is being organised for CPG members.

3. The Convener introduced guest speaker Dr Linda Stephen, Associate Specialist and Honorary Clinical Senior Lecturer from the Epilepsy Unit at the West Glasgow Ambulatory Care Hospital. The speaker talked about preconceptual counselling and the care of women with epilepsy during pregnancy. The presentation included the following points:

Around 7 in 1000 pregnancies occur in women with epilepsy (WWE) in Scotland – around 400 births per year. Pregnant WWE more likely to have physical and mental ill health and social problems, have higher risk of morbidity and mortality and the foetus can also be affected. If they are on AEDs, they are more likely to give birth to a child with foetal malformations.

There are a number of guidelines available on how to manage WWE in pregnancy, including the SIGN guidelines, RCOG Green Top Guide and Best Start from the Scottish Government. It cannot be emphasised enough that the key to delivering a healthy baby is planning. WWE with need to plan their pregnancies; unfortunately around 50% currently do not. It is important that GPs refer pregnant WWE to an epilepsy clinic as quickly as possible, so they can look at the women's medication and seizure control and to rationalise their management and form a plan. In addition to verbal information, written information should be given and cover topics such as seizure control, medication and folic acid use.

Seizure control in general improves in pregnancy for the majority of women. If the woman is seizure free before becoming pregnant then the chances are that she will remain controlled during pregnancy. Taking folic acid in early pregnancy lowers the risk of having a baby with a

neural tube defect – however in WWE this is even more so. It is not fully understood how AEDs interact with folic acid, but some may increase folic acid 'turnover', therefore it is recommended that WWE take 5mg dose prescribed by the GP, ideally from before they conceive and for at least the first 12 weeks gestation.

In the general population, 2-3% of women will give birth to babies with congenital abnormalities. For WWE taking epilepsy medication, the rate rises to 7-8%. Different medications, the number used and their doses will cause different abnormalities; the worst of these is foetal anti-convulsant syndrome.

If a pregnancy is planned, a woman's medication can be altered before she becomes pregnant. Most women will be advised to continue taking medication, but not all, and some whose seizures are well-controlled may have their medication ceased for the first few weeks of pregnancy while the foetus is forming, followed by a smaller dose in later pregnancy. It is a careful balance not to let seizure control deteriorate. One medication and at the lowest effective dose is best where possible; some foetal abnormalities are related to the dose given. Splitting doses throughout the day may also help prevent defects. However medication changes have to be balanced against seizure control, as seizures can put the woman and her baby at risk. Also, blood concentrations of some drugs will fall during pregnancy and so the woman may actually be advised to increase her dose – this can be psychologically very difficult for some women.

Sodium valproate is the most effective drug for genetic generalised epilepsies and unclassified epilepsies, however unfortunately it can be problematic for pregnant WWE. In 2008 a study of 2097 WWE taking valproate revealed that 10% gave birth to babies with congenital abnormalities. Women on higher doses and those taking valproate with other epilepsy medications were at higher risk. This was a 40 year study, however there was no data on folic acid use.

In addition to bodily abnormalities, there are also cognitive problems in some children. Four years ago a study was published which followed 224 children born to women with epilepsy until they were 6 years old. IQ was significantly lower in children whose mothers had taken valproate whilst pregnant compared to several other drugs. It also found that verbal language impairments, autism and ASD were significantly increased in the children of women taking valproate, and that they were more likely to have neurodevelopmental disorders. As a result, the MHRA produced a set of guides for clinicians and patients. In autumn 2017 the EMA held a public hearing and a specialist advisory group to work out what could be done to inform women who are taking valproate.

It is recommended that care of pregnant WWE is undertaken in a unit with access to an obstetrician with a specialist interest in epilepsy and an epilepsy specialist nurse. If a woman needs to be admitted to hospital before or after birth, she should not be placed in a single room due to the risk of SUDEP. Birth and antenatal planning are essential and delivery is best in a consultant-led maternity unit. Seizures during labour and birth are uncommon.

During 2013-15, 14 women with epilepsy died in UK and Ireland during or just after pregnancy. Of 9 cases which were reviewed, 8 had uncontrolled seizures and 5 were not taking epilepsy medication. It was concluded that 52% may have benefited from improved care. It is not possible at this time to ascertain how many of these deaths took place in Scotland. In looking at women who had survived 'near misses' during pregnancy, having shared care between obstetricians and neurologists was a common feature in survivors.

Postnatal care is also important for WWE. Health visitors are educated in supporting new mothers with epilepsy and epilepsy clinic appointments are often around 3 months, at which

point clinicians can discuss seizure control, medication, baby care and safety at home. Around 12% of women suffer from post-natal depression, however in epilepsy this is up to 35%. The diagnosis can be missed, despite the fact there are effective treatments available.

Collecting information about epilepsy and pregnancy is difficult for ethical reasons. A UK and a European epilepsy pregnancy register exist, which enables us to follow up what happens with women's pregnancies, their medication and deliveries and we can follow up the child also.

Following the release of the epilepsy SIGN guidelines in 2015, a working group obtained some funding to publish leaflets and postcards which were distributed to all 290 community pharmacies in Glasgow and given to WWE of childbearing age with their prescriptions over the next year. A follow up survey found that 74.5% of the pharmacists felt this was useful. We also produced posters for display in community pharmacies, GP practices, sexual health clinics and obstetric clinics, encouraging women to contact us directly. Our pre-conceptual counselling appointments also increased following the initiative. We have recently managed to have some extended information included within the Ready Steady Baby book which is given to expectant mothers in Scotland. There is a wide array of people who can help WWE in pregnancy. The question is how we make that difference.

The Convenor thanked the speaker and opened the meeting to questions and comments:

Brian Rocks asked whether all doctors and nurses would know how to deal with a patient having a seizure during childbirth? Dr Linda Stephen (LS) said that obstetricians were trained in dealing with seizures in pregnancy, so yes hopefully they should know how to respond

Yvonne Leavy, Epilepsy Specialist Nurse, pointed out that the women who died during pregnancy seemed not to be under anyone's care, did LS think there is a public health question about how to reach people who are not currently attending any clinics? Also, do we need a working group in Scotland to take forward issues such as the information leaflet pilot and postnatal care in the crucial first 72 hr period, and to potentially adopt things like the shared care document? LS agreed there are definitely women who we are not reaching - the pharmacy project was one attempt to do that. She agreed that the postnatal is vulnerable time when women at risk of SUDEP and morbidity, agreed that a working party would be valuable and certainly looking at a standardised shared care document.

Dr Aline Russell, consultant neurophysiologist, asked about reaching clinicians in primary care to increase their knowledge. LS acknowledge this was difficult, particularly since the demise of the epilepsy QOF points which incentivised GPs to connect with people with epilepsy. LS commented that we need to educate colleagues in general practice, and finds she is invited to take to GPs less often now. KG said he found it quite alarming that GPs wouldn't necessarily refer someone to an epilepsy specialist if they presented pregnant and he felt there was an issue around joined up care there.

Anissa Tonberg asked if a WWE who has otherwise been managed in primary care presents pregnant to a GP, how quickly are women able to be seen by a specialist? (E.g. in the first trimester). LS said could only speak for own health board but felt women could be seen faster, for example if a woman has not been seen in neurology for more than a year then they are regarded as a new referral and go back on the waiting list, it can be tricky to pick out these women. This is also an issue for women who need preconceptual counselling as by the time they come to be counselled, they may already be pregnant.

Chris Jeans, SUDEP Action, felt that girls could receive preconceptual counselling from long before the age they would consider conceiving, and that it should be raised at each appointment.

LS said that at her clinic they try to repeatedly counsel women from the time of diagnosis onwards.

Susan Duncan, consultant neurologist, suggested that women with epilepsy of childbearing age across Scotland be given a leaflet along with their epilepsy medication each time they collected their prescription, like the one that LS and her group devised. She also suggested checking health board prescribing databases to identify women of childbearing age on epilepsy drugs and every 6 or 12 months remind their GPs that she may require counselling. It is a simple idea but requires some money and may also require community based health teams to visit women as she suspects that those at highest risk may have chaotic lives which prevent them from attending hospital for clinic appointments.

Kamath Tallur, a paediatric consultant neurologist, said that his paediatric colleagues had raised big concerns that sodium valproate remains an excellent drug for some epilepsies, sometimes the only one which is effective, and they are worried about being prevented from using it. He wondered if there was a common sense approach that could be used rather than a 'blanket no', particularly with female children who may otherwise die of SUDEP or other things as they lack an effective medicine. LS agreed and gave the example of one of her patients who had died 3 years ago coming off sodium valproate as, in some patients, other drugs are not as good at controlling seizures in genetic generalised epilepsies. She said that sometimes if she has a woman with very difficult to control genetic generalised epilepsy and they have tried every other alternative, she will give them a little bit of sodium valproate but only with careful counselling, making sure she understands the risks, and then if she is controlled and wants to become pregnant they will reduce or take her off for first few weeks or whole of pregnancy.

Lesslie Young, Epilepsy Scotland, referred to discussion of joined up care and pointed out that we lack a full compliment of epilepsy specialist nurses in Scotland, suggesting that this is an area which requires investment and focus. KG agreed with her and reminded attendees that the CPG invites the Minister for Public Health to a meeting each year and it is worth thinking about the issues we would like to raise with her. He mentioned examples from this meeting such as referrals from GPs, waiting time, lack of specialist nurses.

Eleanor Arthur, an Epilepsy Specialist Nurse (ESN), pointed out that issues such as preconceptual counselling, safety and SUDEP are discussed with patients when they are referred to nurse specialist service either when newly diagnosed, or if they are under care of the service, and if the patient is discharged it is made clear that they should be referred back if they wish to plan a pregnancy. Her experience has been that if a woman has previously had contact with the nursing service, she is more likely to contact them when she is thinking of having a baby and seek advice in order to be referred back into service. She agreed it as important to raise the profile and awareness of epilepsy nurses and what they can contribute to care.

Susan Yule, ESN, agreed there could be a better system to fast track pregnant WWE to see a specialist as there is sometimes a delay in them being seen. She commented that she is in liaison with Quarriers to devise practice nurse training to be a point of contact in identifying and referring women back into the epilepsy service.

KG said there seemed of be a diversity of practice in Scotland asked if there was a geographical area of best practice which other boards could learn from. LS said could only comment on own board and said that in general the central belt provision was better, though even here there are issues about how quickly women can be seen by a specialist. KG felt that remote and rural areas were of particular concern.

Pauline Smith, ESN, said that NHS Tayside were fortunate in having a dedicated monthly obstetric epilepsy antenatal clinic where a neurologist and epilepsy specialist nurse input as necessary and there is midwifery care. The community midwives most commonly refer into the service, however there remains a cohort of patients at risk of missing out on preconceptual counselling through not being in contact with the epilepsy service, either because their seizures are well controlled, or they have not been attending clinic appointments and have therefore been discharged. She felt those women were high risk and may benefit from a roll out of the pilot which took place in Glasgow.

Yvonne Leavy mentioned that in Lothian they have a shared clinic which has become a well-known contact point which people will access through lots of routes and where they can be fast-tracked. If you make a service well known or have a single combined service, you are more likely to pull in a bigger cohort. She felt there should also be a public health campaign to capture women not using services. Also, rather than having women cared for by neurologists, ESNs and obstetricians separately, that it was good to combine clinics.

Anissa Tonberg asked the Chief Pharmaceutical Officer what kind of role, under Prescription for Excellence, she felt community pharmacists will play going forward? Rose Marie Parr said she welcomed the examples outlined already involving community pharmacists in Glasgow, which we could build on. She felt it important to work opportunistically, such as giving leaflets alongside medication and when community pharmacists are able to speak to patients, which could be built on further. The Scottish Government (SG) may be able to offer some help around sodium valproate issues. The MHRA have the reserved powers for UK medicine licensing, but the SG can help to see if there are any Scotland-specific issues around pregnancy planning and how to use these drugs. Her team are happy to help with any community pharmacy issues.

KG opened the floor to any general comments from CPG members. Michael McCulloch raised the issue of claiming Personal Independence Payments and reflected on the experience of his daughter. He had grave concerns about the process itself and the effect it had had on his daughter and asked if the CPG could address this.

This was echoed by Jeremy Balfour MSP who explained that benefits such as PIP, DLA and Attendants Allowance are being devolved to the Scottish Parliament and that a Bill is currently going through parliament. Jeremy sits on the Social Security committee and is a former tribunal member. He feels people with epilepsy struggle to get PIP because of the way the current regulations are drawn. He suggested that the CPG invite Jeanne Freeman, Minister for Social Security along to a meeting to address some of these issues. He explained that the Bill will be passed some time before the summer recess and then regulations for each of the 12 devolved benefits will be produced over the next 2-3 years, before the next 2021 election. He felt it would be helpful for the CPG to address how epilepsy fits into the assessment criteria; as it stands at the moment it is in theory almost impossible to get awarded PIP for epilepsy and this causes a lot of people difficulty. He felt it would be helpful to articulate this to the Minister to help ensure epilepsy does not 'slip through' again. Things are not going to change imminently, however he felt the CPG would do well to put down a marker on the issue in the coming months.

KG thanked the speaker and attendees, and said that the next meeting will be on 26<sup>th</sup> April, when our speaker will be Dr Richard Chin of the Muir Maxwell Centre to talk about using medical cannabis to treat epilepsy. He then closed the meeting.