

Draft Note of Meeting – Cross Party Group on Epilepsy, 25 April 2013

In Attendance:

Guy Armstrong, UCB Pharma	Paul Mullan, Quarriers
Jean Barclay, Epilepsy Scotland	Alison McInnes, MSP
Richard Chin, University of Edinburgh	Caterina O'Connor, West of Scotland & Tayside Epilepsy MCN
Kenneth Gibson MSP	Allana Parker, ECS Secretariat
Janet Henderson, New Directions, West Lothian	Jennifer Simpson, Special Products
Hugh Henry MSP	Richard Simpson MSP
Andrena Hughes, Observer	Jacqui Telfer, Epilepsy Scotland
Claire Leonard, Epilepsy Connections	Anissa Tonberg, Epilepsy Scotland
Ann Maxwell, Muir Maxwell Trust	Murray Tyrrell, Observer
Claire Miller, Observer	David Walter, UCB
Nanette Milne MSP	Jean Urquhart MSP

Apologies:

Lynn Allan, Paediatric ESN, Lanarkshire	Hilary Mounfield, Scottish Epilepsy Centre
Matt Barclay, Community Pharmacy	Eileen McCubbin, ESN
Marilyn Bryce, Non MSP Individual Member	Duncan McNeil MSP
Gerard Gahagan, Scottish Epilepsy Centre	Gail Patrick, Observer
Jennifer Irvine, ESN, NHS Lanarkshire	Gemma O'Hare, Scottish Epilepsy Initiative
Hanzala Malik MSP	Linda Radcliffe, ESN LD, NHS Greater Glasgow and Clyde
Helen Macdonald, Lanarkshire Epilepsy Support Group	Nicolas White, Quarriers
Peter Martin, Observer	Lesslie Young, Epilepsy Scotland

1. Deputy Convenor Alison McInnes MSP welcomed attendees and chaired the meeting and AGM for Convenor Kenneth Gibson who was attending a commemorative event for Brian Adam MSP.
2. The draft note of the January 2013 meeting was approved. She gave an update on activities:
 - Since January there have been 8 parliamentary questions involving epilepsy and 3 members' motions including one for International Purple Day by Richard Simpson MSP.
 - Alison was pleased to inform the group that Jean Urquhart MSP was a new member.
 - The Convenor wrote to the Minister for Public Health's Office asking about the audit process for social work services. Mr Gibson also requested that the Minister address continuation funding for Epilepsy 12's extended audit of Scottish paediatric services.
 - The Information and Statistics Division of NHS National Services Scotland is being asked to identify how many older people with epilepsy have unplanned admissions to hospital.
 - MSPs are in the process of securing cross-party support to have a debate on epilepsy hopefully during National Epilepsy Week. The focus will be the Stamp out Stigma schools first aid and awareness campaign which was outlined by MSYPs at the last meeting.
 - The Group has an opportunity to visit the Scottish Epilepsy Centre in Govan on Tuesday 14 May.
 - Our joint meeting with the Mental Health Cross Party Group takes place on Thursday 23 May at the earlier time of 12.30pm in Committee Room 4
 - At the request of the Epilepsy Consortium Scotland (ECS) the Convenor has agreed to write to Directors of Education and ask what first aid and epilepsy awareness training is provided in local schools. This information will help to inform the forthcoming members' debate.

- Evaluation sheets for today's meeting have been handed out. Alison asked everyone to take a few minutes to complete it before leaving.
3. **2013 AGM** – Alison said the Annual Report shows the different ways we are keeping epilepsy at the forefront of Scottish Government thinking and how issues are being highlighted within the Parliament. Since the last AGM on 26 April 2012 the Group has looked at various issues:

Epilepsy and dementia with the links between the two detailed by Dr Andrew Elder, Consultant in Acute Elderly Medicine at Edinburgh Western General. As the population ages, dementia becomes more common and the prevalence of epilepsy and dementia is strongly age-related. Three things might help in the future: a Scottish study of older people, raising awareness with health professionals, and educating key groups such as carers and care home staff.

Developing epilepsy services as outlined by the Minister for Public Health Michael Matheson. He mentioned awareness training within the licence trade, the implementation of neurological clinical standards, access to specialist nurses, the Epilepsy12 UK audit of paediatric services, and the future integration of health and social care services to ensure better outcomes for people with epilepsy.

The “Stamp out Stigma” campaign being launched this summer by Member of the Scottish Youth Parliament David Kerr and Sian Hughes. It calls for pupils' awareness of first aid and long term conditions and disabilities like epilepsy to become a compulsory part of the Personal Social Education curriculum.

Since April 2012, Group members have been instrumental in:

- Arranging for a Members debate for Thursday 24 May during National Epilepsy Week 2012 on the Glasgow Epilepsy Genetics Service and related issues around epilepsy specialist nurses.
- Updating MSPs about current numbers of epilepsy specialist nurses with information provided by specialist nurse Sheena Bevan (ESNA).
- Securing Minister for Public Health, Michael Matheson's agreement that he would write to the Scottish Ambulance Service about what training is provided to both paramedic staff and non-paramedic (patient transport) staff on epilepsy.
- Asking the Public Health Minister both about the audit process for Scotland's social services and if existing benchmarks could be further developed in delivering councils statutory requirements for child and adults with epilepsy.
- In National Epilepsy Week 2012, 74 MSPs wore gold medals for an 'epilepsy and achieving your goals in life' photo call to raise awareness of epilepsy issues within the Parliament.
- Many MSPs visited the 2012 ECS information display in the Members Lobby.
- There has been growing support among parliamentarians for International Purple Day; 56 MSPs were either sporting purple ribbons in Parliament this year (2013), had signed Richard Simpson's Members Motion, promoted the awareness day in the local press and/ or took part in a community radio interview to talk about epilepsy.
- MSPs have asked 11 Parliamentary Questions since the last AGM (124 since 1999). There were also 8 Members Motions involving epilepsy over the last 12 months.

During next year the Group is planning:

- To further raise the profile of epilepsy in the Parliament – if there are topics you would like MSPs to consider please contact the Secretariat.
- To promote 2013 National Epilepsy Week-related activities with an MSP photo call on 16 May after FMQT and having an ECS Garden Lobby exhibition (14-16 May). It's been an active year for the Group. The Deputy Convener acknowledged the contribution made by all those who attend the CPG on Epilepsy. She also thanked the Secretariat provided by Epilepsy Scotland, on behalf of the Epilepsy Consortium Scotland.

Treasurers Report – No income was received or spent directly by the Cross Party Group on Epilepsy since the last AGM in April 2012. However, the Epilepsy Consortium Scotland (ECS) has provided assistance through a Secretariat and has met direct administration costs for mailing, briefings, catering, travel and speakers' expenses amounting to £739.60 for Epilepsy Group meetings in the last 12 months (April and September 2012 and January 2013).

Nomination and Election of Officers for 2013 - The Convener handed over to the Secretariat for the nomination and election of office bearers. The Secretariat read out the sole nominee for each post:

- Kenneth Gibson MSP was re-elected as Convener, proposed by Alison McInnes MSP and seconded by Nanette Milne MSP
- Alison McInnes MSP was re-elected as Deputy Convener, proposed by Kenneth Gibson MSP and seconded by Jean Urquhart MSP
- Richard Simpson MSP was re-elected as Deputy Convener, proposed by Alison McInnes MSP and seconded by Kenneth Gibson MSP
- Nanette Milne MSP was re-elected as Secretary by Alison McInnes MSP and seconded by Kenneth Gibson MSP

MSPs agreed that Epilepsy Scotland continues to provide the Secretariat and thanked everyone for their valued support and contribution to the meetings.

AGM was concluded.

4. Alison introduced guest speaker Dr Richard Chin, Senior Clinical Lecturer and Director of the Muir Maxwell Epilepsy Centre at the University of Edinburgh.
 - Dr Chin began by explaining that the Muir Maxwell Epilepsy Centre is helping people find better management and understanding of epilepsy. In a collaboration between the University of Edinburgh, the Royal Hospital for Sick Children and the Muir Maxwell Trust, the Centre “without walls” offers expertise in clinical medicine, pre-clinical medicine, public health and social science. The collaboration is not just within Edinburgh but extends currently to London (Great Ormond Street Hospital) and the Norwegian Institute of Public Health. The Centre looks at epilepsy across all age groups - from within the womb and up to the elderly.
 - There are three cardinal areas for research; firstly, epilepsy is much more than seizures so finding out exactly how common cognitive and behaviour problems are and what underlie these problems is important. Secondly, even with the progress in genetics, there is need for identifying the cause(s) for epilepsy since in 70% of epilepsy cases the cause remains unknown. Thirdly, 3 in 10 people with epilepsy do not respond to current treatments with medication or surgery; ways to address this are needed.
 - The Centre’s research themes are focussed on these three major areas. These themes are: (1) the psychosocial aspects of the condition including and quality of life or educational impact (2) early life exposures and how they affect epilepsy, and (3) improved epilepsy treatments. The Centre is involved in several projects.
 - A study with colleagues in Norway to research early life exposure shows, for the first time ever, how frequently epilepsy appears in a number of diagnosed neurodevelopmental disorders with 40% of children with epilepsy having autism, cerebral palsy, ADHD, and specific language impairment.
 - A collaboration study with London colleagues on school aged children with epilepsy found, around 12% of people had been diagnosed with ADHD prior to the study but on formal neuropsychology testing 70% had attention and hyperactivity problems. These results confirm that there are some children with epilepsy with problems that are not severe enough to reach a diagnostic threshold. This represents a huge treatment gap because there are clearly unmet needs. Assessment of such needs are done best pre-school since it would aid early detection and intervention.
 - An innovative neuro-profiles study will look at the psychological, cognitive and behavioural problems in pre-school children under the age of 5 in Fife, Lothian and Edinburgh. From 1 May 2013, all newly diagnosed children with epilepsy in this age group will have detailed psychological assessments.

Eye tracker equipment (shown) and possible MRI scans may help to identify specific biological markers for cognitive and behavioural problems. .

- In neuroimaging, scientists in Edinburgh have developed a novel way to determine what areas of the brain are linked with each other (known as diffusion tensor imaging). This should assist epilepsy surgery by providing a clearer and more exact picture of where to operate when removing brain tumours. Special software recently acquired for this at Sick Kids is being evaluated.
- We also know that epilepsy affects the families. A qualitative study on how epilepsy affects families is being led by Edinburgh University social scientist Jeni Harden. She is examining the impact on parents and siblings of affected children. A further medico-sociological project, funded by the Scottish Government, includes working with Epilepsy Scotland to review how people are given information on sudden unexpected death associated with epilepsy (SUDEP).
- Dr Chin pointed out that the work in the Centre is not done just by medics. A project, sponsored by the Roald Dahl Foundation, is looking at Vitamin D and its association with epilepsy. Edinburgh Sick Kids Epilepsy Nurse Consultant, Celia Brand will complete the first phase by the end of 2013
- In the past decade there has been a 10 per cent decline in the incidence of epilepsy recorded in GP surgeries. Possible contributory factors may involve better diagnosis, public health interventions, better immunisation, fewer cases of brain injuries due to fewer road traffic accidents, and better antenatal care. These all highlight that to make a difference in the epilepsy field we need to consider environmental causes and address these issues, along with genetics. This is not just a UK phenomenon as other countries are seeing a decrease in childhood epilepsy. Work from Finland also reveals an increase in epilepsy among older people, a subject discussed in a recent CPG meeting associating the link between dementia and epilepsy.
- Sterling work is done at the Glasgow Epilepsy Genetics Service regarding the cause of epilepsy. Information on some new gene mutations and specifically about Dravet Syndrome has been the cornerstone of their work. However, in 95 per cent of cases of these genetic forms of epilepsy they have not been acquired from mum, dad or anyone in the family. The question is why are these new spontaneous genetic mutations happening?
- Exposure to environmental factors in early life may be the answer. Experimental data shows how stress and anxiety can interfere with neuro-development as can drug abuse and social drug use. Contributory factors such as diet and childhood infections are certainly something to consider.
- Some forms of epilepsy are due to brain malformations. With cortical dysplasia, the changes in brain tissue are similar to the changes seen in the early stages of cervical cancer. A known association between human papilloma virus (HPV) infections and cervical cancer, as evidenced in research, may help to explain how such an infection may actually cause this brain malformation. Protecting teenagers against cervical cancer may also protect their children from being infected with this HPV virus and causing a specific form of epilepsy.
- To help address the issue of influential prenatal factors, the Centre is doing a large study with its Norwegian colleagues to look at prenatal risk factors for epilepsy. The Norwegian cohort has recruited 110,000 mothers (during pregnancy) with biological samples and detailed pregnancy data. This may show risk factors affecting neuro development in general. Some preliminary data shows that if women smoked during pregnancy they have an almost 50% greater risk of having a child with epilepsy. If they did not breast feed or for less than 6 months, that risk rises to 50 and 80% respectively suggesting there are modifying factors.
- A new British Birth Cohort Study, funded by the UK Government will provide opportunities for research by both the Centre and the Scottish Paediatric Epilepsy Network. Opportunities for work in adults will be facilitated by a recently established database for adult epilepsy by colleagues in Edinburgh at the Western General Hospital.
- In addition to Scotland having a world leading centre in genetics, it is also renowned for health informatics and being able to link health data right across the country. A Scottish TIME project being lead by the Centre is looking to see if birth delivery outside of regular hours increases the risk for hypoxia (less oxygen

reaching body tissues) associated with epilepsy. The project uses routine data collected by NHS ISD (Information and Services Division). By doing secondary analysis on it, a virtual database of epilepsy cases can be established. Research will be able to look at time trends, regional variation and the effect of specific interventions eg epilepsy nurse specialists.

- Scientists at Edinburgh University have discovered a novel method of how nerve cells recycle chemicals needed for nerve cells to communicate with each other. Abnormalities in this pathway have been shown in brain slices and in animal models to cause severe seizures. Given 3 in ten people do not respond to current treatments, the Centre is investigating this new pathway as a target for new anti-epilepsy treatment in humans.
- Dr Chin ended by saying that the Centre is not about bricks and mortar it's about people. The main mission of the Centre is about early diagnosis and early intervention and by its very nature the Centre is multi-disciplinary and inter-disciplinary and fosters a collaborative atmosphere within Edinburgh, within Scotland and beyond.

5. The Depute Convener thanked Dr Chin for his fascinating presentation and invited questions: Nanette Milne MSP asked if there is a case to be made for immunising all women of reproductive age against HPV given these implications? Dr Chin said it would be very selfish in just thinking about immunisation to protect against epilepsy in isolation, however, he agreed there is a strong argument for such immunisation given the benefit for other conditions.

Murray Tyrrell asked if economic issues featured among the environmental factors being looked at, such as differences within a range of social backgrounds? Dr Chin confirmed much work is going on regarding social economic deprivation. It is an area the Centre is exploring. Preliminary study data from Norway suggests a worsening socio-economic state does have an influence. Exactly what aspect(s) contribute, for example diet or maternal stress, are areas to tease out and will take time. The Centre is considering how the environmental affects genetics.

The Deputy Convener noted Dr Chin's explanation of how important it was to offer a detailed psychological assessment and then look at different cognitive and behavioural problems. MSPs and other health professionals know that getting support for people can be a problem. She asked about the Centre's dialogue with the rest of the health service, given that a new cohort of people are being identified in need of support when others are not getting co-ordinated support now. Dr Chin responded it was a catch 22 situation for in looking only at the diagnosis, the need could be underestimated 7 fold; it is difficult to argue for resources without robust data to inform the NHS.

Dr Chin was further asked whether the Centre was a local or national centre. He said it was multi-disciplinary and inter-disciplinary within Scotland and beyond the UK. While most of the work is based in Edinburgh, the Scottish TIME study is a national project.

6. The Deputy Convener invited organisations to share any updates:

Paul Mullan updated everyone on the opening of the William Quarrier Scottish Epilepsy Centre by the Deputy First Minister. Five patients are there now. An Epilepsy Group visit to the new centre will take place on 14 May and all are welcome to attend. A separate visit can be arranged for those unable to make that date.

Ann Maxwell gave the latest details on the genetic service in Glasgow. A drug used to treat obesity was removed from use. Research in Belgium on this 'orphan' drug shows it may be effective as a treatment for Dravet syndrome. Funding that has been procured by the company in Belgium and a second stage drug trial is now being done in conjunction with Glasgow.

7. Alison thanked everyone for their contribution and reminded MSPs to visit the ECS exhibition from 14-16 May in the Garden Lobby for any information and details about National Epilepsy Week. A National Epilepsy Week photo call takes place on Thursday 16 May directly after FMQs.
8. The **next Cross Party Group for Epilepsy** meeting will take place on **Thursday 26 September** at 1pm. Please forward any ideas for topics for that meeting to Allana Parker, Secretariat.