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**Note of Meeting – Cross Party Group on Epilepsy, 27 September 2012**

**In Attendance:**

Noreen Ahmad, Observer	John Macgill, GSK
Guy Armstrong, UCB Pharma	Ailsa McLellan, Consultant Paediatrician
Jean Barclay, Epilepsy Scotland Board	Megan McTiernan, PA to Kenneth Gibson
Sheena Bevan, ESN & NHS Grampian Orkney & Shetland	Craig Miller, PA to R Simpson MSP
Adrienne Burgess, Observer	Nanette Milne MSP
Richard Chin, Epilepsy Research Centre	Hilary Mounfield, Scottish Epilepsy Centre
Alison Culpán, GSK	Paul Mullan, Quarriers
Bob Doris MSP	Caterina O'Connor, West of Scotland & Tayside Epilepsy MCN
Helen Eadie MSP	Allana Parker, Secretariat
Gerard Gahagan, Quarriers	Richard Roberts, Epilepsy Scotland
Kenneth Gibson MSP	Dennis Robertson MSP
Diane Godwin PA to Dennis Robertson MSP	Derek Robertson, ELN
Stacey Heggie, Royal College of Paediatrics	Dr Richard Simpson MSP
Donald Mackintosh, ESN	Dr Jane Stuart, Pennywell Resource Centre
Michael Matheson MSP, Minister for Public Health	Jacqui Telfer, Epilepsy Scotland
Ann Maxwell, Muir Maxwell Trust	Anissa Tonberg, Epilepsy Scotland
Peter Martin, Observer	Nicolas White, Quarriers
Lesley McCallum, Scottish Epilepsy Initiative	Lesslie Young, Epilepsy Scotland

**Apologies:**

Lynne Allan, Epilepsy Nurse	Lorraine MacKenzie
Claire Baker MSP	Hanzala Malik MSP
Marilyn Bryce, Non MSP Individual Member	Shirley Maxwell, Epilepsy Connections
Ruth Davidson MSP	Eileen McCubbin ESN
Neil Findlay MSP	Jamie McGrigor MSP
Murdo Fraser MSP	Duncan McNeil MSP
Gina Freeman, New Directions West Lothian	Ruth Nicholson, Viropharma
Janet Henderson, New Directions West Lothian	Willie Rennie MSP
Jamie Hepburn MSP	Jennifer Simpson, Special Products
Jim Hume MSP	Maureen Swannie, Orkney Health Care
James Kelly MSP	John Toland, ESN Dunfermline
Kevin Kelly, ESN Western Infirmary Glasgow	Sam Whitmore, Epilepsy Connections
Helen MacDonald, Lanarkshire Epilepsy Support Group	

1. Convenor Kenneth Gibson MSP welcomed attendees to the Cross Party Group on Epilepsy and today's guest speaker, Minister for Public Health Michael Matheson.
2. Mr Matheson thanked the Convenor and Group for the invitation to attend the Cross Party Group on Epilepsy. He addressed the meeting:

- Epilepsy was discussed in the Parliament this week. Bob Doris MSP raised the issue at health questions with the Minister, Michael Matheson. Mr Doris outlined Epilepsy Scotland's training initiative for those within the license trade to enable greater awareness when dealing with individuals who have epilepsy. Mr Matheson was more than happy to meet with interested parties and consider how this positive initiative could be built on to a national level
- The Minister was conscious of issues around neurological standards and their implementation across Scottish health boards. In his view, considerable work over the last two years showed that boards were willing to look at improving their level of neurological services. This included service provision for those with epilepsy. To maintain this progress, the Scottish Government has provided £40,000 to establish a new National Neurological Advisory Group some months ago. It will be responsible for continuing to work alongside boards concerning the implementation of local plans, and the Minister will review how this work is taken forward
- Mr Matheson was aware of issues of access to specialist nurses and to specialist epilepsy nurses. He mentioned the positive approach taken by a novel partnership developed between some of the pharma companies, Epilepsy Scotland and a health board for the provision of an epilepsy nurse. He is keen to encourage this kind of approach and it may be a good marker for how things could develop in the future, both for epilepsy and other long term conditions
- Overall, good progress has been made regarding paediatric epilepsy services in Scotland. There is more to be done following audit findings from the recently published Epilepsy12 Report of services across the UK. It detailed some four units in Scotland without paediatric specialist epilepsy nurses. Two boards were now engaging with the Scottish Paediatric Epilepsy Network (SPEN) to see how to take things forward and two other boards have access to a specialist nurse outwith their geographical area.
- Finally, the Minister highlighted the future integration of health and social care services, originally proposed 20-30 years ago. The new integrated agenda will affect how primary care services are managed and the way acute secondary care services interact with these. Such changes will impact people with epilepsy and how they then receive certain services. The key part is making sure that the outcomes for individuals are much better.

3. The Convener thanked the Minister for his presentation and invited questions:

Consultant Ailsa McLellan provided more detail and clarity concerning four units cited without epilepsy nurse provision in the Epilepsy12 Report. The audit period was from November 2009 to May 2010. At that time units in Argyll & Bute, Livingstone, Dumfries & Galloway and Forth Valley reported they did not have a specialist nurse. However, an epilepsy nurse has since been appointed in Livingstone through money from the National Delivery Fund. The Argyll & Bute unit may have misunderstood the audit question and did not mention the access they do already have to an epilepsy specialist nurse in NHS Greater Glasgow & Clyde. SPEN and a number of other agencies, including Epilepsy Scotland, have been working with NHS Dumfries & Galloway and NHS Forth Valley to move things forward, with recent positive developments in Dumfries and the Stirling area.

Mr Matheson thanked Ms McLellan for her helpful update. He expected boards to look at their audit performance. He was also aware that NHS Forth Valley and NHS Dumfries & Galloway were engaged with the Network to consider how they can take this work forward.

ESN Sheena Bevan welcomed what the Minister had to say regarding ESNs. Their numbers have increased with four new epilepsy specialist nurse positions since the last Group meeting (April). These included an Adult ESN in NHS Tayside (full time), Adult ESN in NHS Grampian (part time), a paediatric ESN in NHS Borders and a paediatric epilepsy nurse specialising in epilepsy surgery in NHS Lothian (Sick Children's Hospital). However, more nurses were needed. Neurological standards stated that patients who have had a diagnosis of first seizure or epilepsy should be seen

by an ESN within 30 days of diagnosis. While ever hopeful of meeting this target, there was a long way to go and she welcomed and encouraged health boards to employ more ESNs.

Mr Matheson noted that the level of NHS specialist nurses has increased quite dramatically in the last decade, not just in epilepsy but for a whole range of conditions. Their value is not lost on him. It is important health boards recognise this too, although some of the skills which specialist nurses have can also be utilised in other areas within health care. Increasing ESN numbers is evidence that these boards do recognise their value. He wants to make sure all boards continue to make progress.

Sheena Bevan also remarked that epilepsy nurses were concerned about the down grading of existing posts to save money when experienced ESNs left. The long term result would be less experienced nurses delivering services to patients.

Nannette Mine MSP mentioned she had heard of boards putting specialist nurses back onto general duties given their competency to do this. In her view it was very important, where possible, to keep a specially trained nurse in their specialist role.

The Minister responded that part of a nurse's job within the NHS is to do other things outwith their own specific specialism. A clinical view is it helps nurses retain skills in other areas and is part of the NHS skills mix. He could not give a commitment that ESNs will never do anything outwith their specific specialism because of the way in which the NHS workforces operate.

Anissa Tonberg invited the Minister to comment on the expected level of health board involvement with the National Neurological Advisory Group. This new body is administered by the Neurological Alliance of Scotland to support the continued implementation of NHS clinical standards for neurological services.

The Minister agreed he had provided extra funding for the Neurological Alliance and others, not just to be a watchdog but to help and support health boards to progress their plans in addressing service gaps. He expected boards to engage with the Neurological Advisory Group. In the last two years many boards had recognised the value of establishing services if they were to make further progress.

Helen Eadie MSP asked the Minister about internal monitoring processes by the Scottish Ambulance Service. Before Michael Matheson became a minister, one of her constituents with epilepsy had died in an ambulance because sufficiently trained personnel were not on board. She wanted an assurance that proposed changes following that incident were introduced and were being monitored.

The Minister said the Scottish Ambulance Service is expected to ensure their staff are adequately trained in understanding how to deal with a whole range of different conditions. He was aware of adverse incident reporting when a serious event occurs. A procedure exists to check deficiencies in the system so that lessons can be learned. Progress is now being made so that ambulance staff may have access to a patient's relevant medical records or medical information. This supports staff in their role and helps them check that any medication given is appropriate. Overall, ambulance staff are now trained to a far higher level. While all emergency crew vehicles are largely trained in epilepsy first aid, the Minister does not specify training needs. Instead, national standards are set and the Scottish Ambulance Service is responsible for implementing these when training staff to paramedic level. He agreed to ask the Scottish Ambulance Service for details on whether epilepsy training is part of the training regime for emergency ambulance crews. This may help allay concerns.

Ann Maxwell mentioned that children with complex epilepsy have always been very dependent on the support of social services as well as the NHS. However, progress for the integration of these two organisations has not happened. The Epilepsy12 report has highlighted that Scotland is doing really well, relative to the rest of the UK, in delivering a health service for children with neurological issues. In her view the greatest weakness is social services which fundamentally fail families and children. In planning the move towards integration of the NHS and social services, once the emphasis moved beyond acute care to social services, she believed the latter are not really fit for purpose.

The Minister agreed only pockets of integration had taken place between health and social work over 20-30 years. The important thing was not about local authorities taking over health or health taking over local authorities' functions but making sure both are closely aligned in how they work together. Funding for certain services could be better and be done in a more consistent way. This ensures the outcomes for individuals are better and agencies are working much more effectively together,

Ann Maxwell mooted Scotland doing an audit of social services to see how well they are delivering. The Minister stated there are existing legal requirements on all local authorities for what they have to provide in order to meet their statutory requirements. As a former health professional with many years working in the social care sector, he noted cultural differences between social work and health and how they go about delivering services. Some of the challenges around this agenda are genuine, some are issues which are complex and have to be worked through, some are professional self interest, and these all have to be unpicked to improve the outcomes for individuals using services.

Dr Richard Simpson MSP cited elderly care where £1 in £3 of the NHS budget is spent on unplanned emergency admissions because there is no integrated care programme to keep older people at home. Many subsequently go into care homes. The Holy Grail is to reduce the number of unplanned emergency admissions and release more funds for preventative work. He would like to know how many unplanned admissions there are of people with epilepsy, particularly those with more complex needs. Some of these admissions could be prevented with a properly integrated service that allowed for proper and better support which Ann Maxwell is saying is not there at the present time.

The Minister replied that admissions for epilepsy may well be a small part of general unplanned admissions to hospitals. More people have a long-term condition. Primary care has the capacity to meet that growing demand. It could actually reduce it through better planning and provision at both community and primary care level. The average length of stay in a hospital in Scotland is less than 3 days, which is on par with the rest of the UK. The integration agenda is also important to support the needs of older people. The right support, advice and assistance to help with their mobility can have a massive impact on hospital costs. Some national programmes are being considered for Scotland. These could release resources in acute settings to be better utilised across the NHS.

Ann Maxwell asked how this would benefit children with epilepsy. The Minister responded that freeing up resources in acute care would benefit the whole system. Proper management within a community setting reduces unplanned admissions that put pressure on acute NHS services. This then releases resources which can be used for paediatrics and a whole range of other areas.

Dennis Robertson MSP, an advocate of integrated services for 30 years, wanted the Minister's reassurance that those carrying out the initial assessments are qualified to identify the person's needs and devise an effective care plan for outcomes. He also questioned if patient transport services provided their staff with minimum awareness training about epilepsy.

The Minister agreed to cover this issue in a letter to the Scottish Ambulance Service to follow up on what training is provided to both paramedic staff and non-paramedic staff and how much of that involves conditions like epilepsy. Drafting and agreeing care plans with individuals who require support and assistance would continue to require professional input. There will always be a tension and challenge in the assessment process over need and want.

The Minister mentioned he is very keen to continue the good relationship at Government level with various epilepsy organisations in Scotland. He also thanked this Group for highlighting areas of concern and for everything it was doing to foster progress. He gave a reassurance of his department's willingness to continue to make good progress in assisting individuals with epilepsy.

4. The Convener thanked the Minister and gave his update:

- The note from the April meeting has been circulated and there were no amendments
- Since April, 4 Parliamentary Questions (PQs) and 2 members Motions (M) about epilepsy were put forward by Bob Doris, Richard Simpson and Kenneth Gibson. Topics included:

Hermitage Academy winning Epilepsy Action's education award (M)  
National Epilepsy Awareness Week (M)  
Quarriers survey findings showing 55% of respondents believed discrimination towards them was widespread (PQ)  
Support for people with Angelman syndrome (PQ)  
Any Government review of the misuse of Gabapentin (PQ)  
Asking how the Scottish Government supports people living with epilepsy (PQ)

The Convenor thanked Group members for their activity in this area

- MSP colleagues Paul Wheelhouse and Humza Yousaf have resigned from the Group following their recent promotion to ministerial posts.
- Details of the Epilepsy12 report covering the first UK wide audit of paediatric epilepsy services have been distributed to MSPs by Epilepsy Scotland. Members may wish to raise this matter with their own health boards.
- An Epilepsy Consortium Scotland has been developed, led initially by Epilepsy Scotland. It aims to act as a collective voice for epilepsy-related organisations and individuals in Scotland. It will inform the Scottish Government and other policy makers in matters of health, social care and public policy relating to epilepsy. The Epilepsy Consortium Scotland has been allocated an exhibition space in the Garden Lobby in May 2013, in the run up to National Epilepsy Week, sponsored by the Convenor
- The Department of Health's response to the Group's letter following recent FAI recommendations into the sudden and unexpected deaths of two teenagers will be circulated.

The Convenor asked the Group if they had any comments to make or anything else to share:

Sheena Bevan had brought updates of ESN numbers. She also shared that epilepsy nurses are concerned that some GP practices are charging patients for a bus pass certificate. It accompanies the forms for free bus travel for people who have a diagnosis of epilepsy and are exempt from driving on medical grounds. The certificate only requires a signature by the epilepsy nurse or doctor. The Convenor agreed to take up this issue.

Lesslie Young outlined Epilepsy Scotland's new initiative with the licensing trade. It was a huge opportunity and could have a significant impact on people with epilepsy. This training programme can be rolled out easily to other agencies (police, employers, educators) identified by Bob Doris MSP. There is potential to help a large number of people with epilepsy who inadvertently enter the criminal justice system through behaviour they have no control over.

Bob Doris MSP explained this novel training was a good idea. He contacted Glasgow Licensing Board in relation to epilepsy training and pub owner Colin Beattie agreed all his staff would be trained. Mr Doris is delighted the Minister is going to take this project forward.

Matt Barclay mentioned a medication issue. Pfizer has recently sold a license for making phenytoin to Flynn Pharma which should make the supply of the drug easier to come by. There is no difference at all in the colour or shape of the tablet being supplied although the packaging may change.

5. The Convenor thanked everyone for attending. The next meeting is Thursday 31 January 2013 at 1pm in Committee Room 2. The topic will be the MSYPs campaign for schools where pupils can learn more about first aid, long-term conditions and disabilities. The AGM is on Thursday 25 April when the Group will hear about the work of the Muir Maxwell Epilepsy Centre. If people have any ideas or issues they want to raise, they should contact the Secretariat, Allana Parker.