

Note of Meeting – Cross Party Group on Epilepsy, 24 April 2014

In Attendance:

Declan Ahern, ESNA, Epilepsy CNS	Paul Mullan – Quarriers
Guy Armstrong, UCB Pharma	Caterina O'Connor, West of Scotland & Tayside Epilepsy MCN
Susanne Cameron-Nelson – Royal Pharma Society	Allana Parker, ECS Secretariat
Nitin Desai – GP & Improvement Adviser for Neurology	Derek Robertson – ELN Edinburgh
Cathy Dorrian – SCTT Service Manager	Jennifer Simpson – Special Products
Kenneth Gibson MSP	Jacqui Telfer, Epilepsy Scotland
Cara Hilton MSP	Jean Urquhart MSP
Andrena Hughes, Observer	Nic White - Quarriers
John Macgill – Glaxo Smith Kline	Grant Wright – Epilepsy Scotland
Hilary Mounfield, Scottish Epilepsy Centre	Lesslie Young – Epilepsy Scotland

Apologies:

Matt Barclay, Community Pharmacy	Lorraine MacKenzie, Observer
Celia Brand, Paediatric Epilepsy Nurse	Peter Martin, Observer
Cameron Buchanan MSP	Ann Maxwell, Muir Maxwell Trust
Jo Campbell, ESN Aberdeen	Nanette Milne MSP
Dr Andrew Elder	Alison McInnes MSP
Gerard Gahagan, Scottish Epilepsy Centre	Linda Radcliffe – ESN
Janet Henderson, New Directions West Lothian	Richard Simpson MSP
Jen Irvine, ESN	Jane Stuart, NHS Lothian
Claire Leonard, Epilepsy Connections	Anissa Tonberg, Epilepsy Scotland
Helen MacDonald, Lanarkshire Epilepsy Support Group	Sam Whitmore, Epilepsy Connections

1. Convener Kenneth Gibson MSP welcomed attendees to today's meeting and AGM.
2. The draft note of the January 2014 meeting was approved. He then gave an update on activities:
 - Paul Martin MSP has joined this Cross Party Group
 - Since the last meeting there have been two Members Motions for International Purple Day submitted by MSPs Gil Paterson and Bob Doris.
 - A Members debate on epilepsy has been secured during National Epilepsy Week. The debate on Wednesday 21 May is around stigma and the need for public education. It references the Stamp out Stigma schools first aid and awareness campaign.
 - As previously mentioned, all three epilepsy indicators are being retired from GP contracts. Both Epilepsy Scotland and the Epilepsy Consortium Scotland have raised this matter with BMA Scotland. This issue warrants further discussion and the Group will be informed of its progress.
 - Please remember to complete the evaluation sheet for today's meeting.
3. **AGM** – Packs have been issued to all in attendance which includes a copy of the annual report:
 - The **annual report** shows how the Group is raising the profile of epilepsy within the Parliament and how it is helping to influence Scottish Government thinking on health and education issues. The Secretariat has drafted this year's Annual Return to the Parliament. If there is anything that needs amended or added to it please contact the Convener and Secretariat
 - **Financial Report** – No income was received or spent directly by the Cross Party Group on Epilepsy since the last AGM in April 2013. However, the Epilepsy Consortium Scotland (ECS) has provided assistance through a Secretariat and has met the administration costs for mailing, briefings, catering, travel and speakers' expenses amounting to £730.78 for the Epilepsy Group meetings in the last 12 months (April, May and September 2013 and January 2014).

- **Nomination and Election of Officers for 2014** – 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 Hilary Mounfield and seconded by Lesslie Young
 - Alison McInnes MSP was re-elected as Deputy Convener, proposed by Nic White and seconded by Lesslie Young
 - Richard Simpson MSP was re-elected as Deputy Convener, proposed by John Macgill and seconded by Guy Armstrong
 - Nanette Milne MSP was re-elected as Secretary, proposed by Lesslie Young and seconded by Paul Mullan.
 - MSPs agreed that Epilepsy Scotland continues to provide the Secretariat and thanked everyone for their valued support and contribution to the meetings.
4. The Convener introduced guest speaker Dr Nitin Desai who is a GP working in NHS Dumfries and Galloway. Dr Desai covered the challenges around providing epilepsy care in a rural area:
- Dumfries and Galloway is a very large rural area with a 150,000 population spread over 3,500 square miles. When Dr Desai became involved with improving epilepsy services for the area there had been no neurologist in NHS Dumfries and Galloway for at least 12 months
 - An epilepsy diagnosis was made by various locum consultants, often seeing patients in a Saturday clinic with 20 minute appointments. After this and their initial recommendations for drug therapy, patients were sent back to primary care and their medication was titrated up as best as could be managed by their local GPs. There was no specialist nurse who could monitor their progress, or offer advice and help on a host of issues, such as employment, alcohol, driving etc. There had been a patient self-help group in Castle Douglas, but it had ceased meeting
 - Dr Desai surveyed GPs and practice nurses who were doing primary care epilepsy reviews and very few GPs and no nurses had any up-to-date training. Part of his role was to help NHS Dumfries and Galloway implement Health Improvement Scotland standards for neurology, including epilepsy. Among these were that a diagnosis should be made by an epilepsy specialist, that all primary care reviewers for epilepsy should have training every 5 years and that there should be an epilepsy specialist nurse available for ongoing education of staff and patients, as well as monitoring patients with epilepsy
 - Graham Battie, a colleague in Learning Disability (LD) had met Epilepsy Scotland to talk about a project to improve staff education and training because a very high proportion of LD patients have epilepsy. Dr Desai and his quality improvement colleagues got involved
 - A partnership project was discussed for an epilepsy specialist nurse (ESN), employed by Epilepsy Scotland, (but funded by pharmaceutical companies), to work in NHS Dumfries and Galloway for three years, to develop service provision. In particular, this ESN would educate staff in primary and secondary care and Learning Disability, then educate patients and help form patient groups to help each other and advocate for better services
 - The health board management were very sceptical and did not want any involvement with pharma. After much persuasion, Epilepsy Scotland's chief executive Lesslie Young proposed a tripartite agreement which would hold all parties to account to fulfil their role and that no covert sponsorship of particular medicines would be allowed. NHS Dumfries and Galloway agreed to get involved and the project began in 2012
 - A number of positive things have been done since ESN Grant Wright started. He does not see patients in a clinical way but provides education. In terms of primary care, the majority of staff have now had training in epilepsy education, with nurses and GPs feeling more confident in doing annual reviews, and a survey of practice nurse educational needs has been completed
 - An epilepsy audit tool has been developed plus an audit of care was completed in two practices, (a large Dumfries practice and a small rural practice). A 'Good Practice Guide' and 'Aide Memoir' for epilepsy annual reviews have been developed. There is signposting/links to information and resources available from Epilepsy Scotland on the local NHS intranet
 - In secondary care, the National Audit of Seizure Management in Hospitals (NASH2) showed this health board did quite well and is above average for seizure care in adults. The education of secondary care staff is helping. ESN Grant Wright holds patient education and information

sessions at Dumfries & Galloway Royal Infirmary. This need was identified by the new neurologist Dr Dolezal

- For patients and carers, there is epilepsy representation on the Neurological Voices Group. There has been a development of hand held records, local education events and wider community educational events, while some support groups and networks are beginning to be established. A patient/carer satisfaction survey has been undertaken
- For Learning Disability services, an epilepsy care plan was developed along with rescue medication protocol templates. Education and training has been delivered to resource centre and respite care staff, as well as psychiatry and LD inpatient service staff. A newly developed LD epilepsy service runs in conjunction with neurological services
- Pathway mapping has been undertaken to record existing services and make recommendations for service improvement
- This innovative tripartite agreement between pharma, Epilepsy Scotland and Dumfries and Galloway health board has brought about a step change in the provision of services for epilepsy patients. It has vastly improved the skills of primary care, secondary care and learning disability staff. It has also led to education and support for patients and carers and will leave a lasting legacy at its conclusion in 2015.

5. The Convener thanked Dr Desai for his presentation and invited questions:

Declan Ahern commented that he was concerned that as ESNA representative for Scotland neither he nor any of its members as far as he was aware had any communication from NHS Dumfries and Galloway or Epilepsy Scotland regarding an epilepsy nurse specialist. He would share the Trust's concern regarding pharma funding. He asked about Grant Wright's employer which is Epilepsy Scotland. Declan has concerns regarding the project outcomes and its potential use given that this is a private enterprise funded by another organisation out with the NHS. He absolutely applauded the work, and the very big need for ESNs everywhere and in particular in Dumfries & Galloway where there have been none. He asked about future funding for an ESN post and if any neurologist was trying to push that forward.

Lesslie Young responded that a business model was developed as a result of a need for a service that wasn't there. She agreed with Declan that the ideal is for an epilepsy specialist nurse post as outlined by Dr Desai. The project's funding is within the ABPI guidance. This clearly states government approval for the pharma industry working with the NHS but the process has to be transparent. A very detailed joint working agreement outlines what is offered by way of financial support, expertise, help in kind etc. The outcomes and deliverables had to be stated from the outset. The NHS, pharmaceutical supporters and Epilepsy Scotland also had to detail their exit strategies.

Lesslie Young commented that one great concern was that the project would leave a gap when it ends in 2015. All the partners agreed when the NHS said that Grant should not have a clinical case load. He does have an honorary contract with the NHS but his employer is Epilepsy Scotland. The project has achieved a huge amount. Information gathered through audit will be presented to the health board and to government about why an ESN is the answer. It will provide other recommendations for them to work on. All stakeholders are aware that the potential gap when the project is complete will need to be addressed. That may be in the form of further partnership working which stills needs to be discussed and agreed. Everyone has one focus and that is to make better the lot of those who have epilepsy. This project could be replicated, not just for epilepsy but for other conditions.

Declan Aherne agreed he did not have a problem working with pharma either. He noted education on self- management, and asked who oversees clinical governance here. Grant Wright said he did not offer patient specific information but sign- posted general information. His work was educating clinicians, nurses, carers and people with epilepsy. Declan thought the person delivering this kind of information needs to have a very specialised background. Grant has worked with learning disabilities and is an epilepsy nurse specialist.

Declan wondered if the health board has viewed this project as a money saving exercise prior to funding an ESN. The Convener hoped that the project will be a catalyst for such a post. Dr Desai believes if there is enough information to justify having an ESN in Dumfries and Galloway the project would be building a case for this. He advised Declan that Grant has a Dumfries and Galloway nurse manager supervising him in terms of line management. Declan made the point that the line manager would have no specific specialist knowledge in managing epilepsy.

Kenneth Gibson MSP asked about any proposals to share the ideas being discussed with other health boards and across wider Scotland. Lesslie Young reports twice a year to the Government on Epilepsy Scotland's work, project outcomes and information gathered. There is an interest from two other similar geographical areas, in Ireland and the Highlands, to replicate this project. The commercial partners don't have to be pharma industries, they could have philanthropic aims. Kenneth is concerned about uneven services for Scotland in terms of epilepsy treatment. He wants to ensure that examples of best practice are adopted and rolled out across the whole country so that several years from now they are in-bedded across Scotland. Lesslie responded that Epilepsy Scotland's ideal is a continuing campaign to have a full complement of epilepsy specialist nurses. Given the different economic landscape, some might describe this project as a compromise but in her view it's a step worth going through to get to the ideal. Kenneth said it was better more people have access to such a service but would like to see it across the country.

Hilary Mounfield remarked there is no doubt the project will provide cost benefits to health boards which is what they understand. A management report could show the number of people who are not sent to A&E or not going for expensive consultancy visits because they are seen and treated by GPs and local services. The bottom line is having this post saves the health board money and that is part of the work for next year. Kenneth Gibson MSP added his view that the best services are always the least expensive all round. Lesslie Young concurred and said one of the tasks lined up is exactly as Hilary described to look at admissions to A&E.

Grant Wright mentioned Dumfries and Galloway is a very attractive area for people to retire to so there is an ageing population. There is also a higher incidence of epilepsy amongst people over the age of 65 which is going to put a bigger strain on local resources. However, this older population responds to certain kinds of treatment with a better seizure freedom rate. Having an ESN post can save money and take the pressure of valuable resources.

Dr Desai thought there was some reason to be optimistic. The health board originally said that there was only funding for one neurologist. When the neurologist came into the post it was apparent that he was extremely overworked and was likely to leave if he did not get help. A second neurologist post is now being advertised. The project has to show that an ESN is needed and the health board can actually save some money in the process. Cathy Dorrian mentioned that tele-clinics were helping Dumfries and Galloway consultant neurologist. This technology can be used for patient education and to avoid lots of unnecessary travel.

Susanne Cameron-Nelson asked how the partnership project engaged with pharmacists in the community. Grant Wright had met with pharmacists and they did some joint work together around best practice. Pharmacists have been very supportive with the audit process around commonly prescribed drugs and the appropriateness of types of medication.

6. The Convener invited any updates from representatives around the table:

Cathy Dorrian mentioned two new tele-clinics for patients with epilepsy- Glasgow to Oban for patients from the Oban/ Campbelltown area, and from Ninewells Hospital Tayside to HMP Perth

Andrena Hughes mentioned the withdrawal of surgery opportunities at Glasgow for children and moving these to Edinburgh. Kenneth Gibson MSP believed the focus for health boards was to have one surgical centre with top quality surgeons doing operations rather than two or three surgical centres Scotland which would possibly dilute the expertise. Dr Desai said the rationale was it demonstrated competency to have super specialists in one location than more centres which would handle a smaller number of operations. Kenneth will look into this.

Hilary Mounfield mentioned the Scottish Epilepsy Centre has now been open for nearly a year.

7. Future dates - MSPs can get information and plan their activities for National Epilepsy Week by visiting the Epilepsy Consortium Scotland exhibition in the Garden Lobby from 20-22 May.

The Members Debate starts at 5pm in the Chamber on 21 May. Contact the Parliament for tickets for the public gallery, or possibly turn up on the day. Allana Parker has the details

This year's National Epilepsy Week theme is transformation. New guidelines for adults with epilepsy, which are gold standards for care, will be launched shortly, MSPs can take part in a Sign up to SIGN photo call on Thursday 22 May directly after First Ministers Question Time.

8. Kenneth Gibson thanked everyone for their contribution. The **next Cross Party Group for Epilepsy** meeting will take place on **Thursday 25 September** at 1-2pm. Please send your ideas for possible topics to the Secretariat and these will be considered during recess.