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### Note of Meeting – Cross Party Group on Epilepsy, 31 January 2013

#### In Attendance:

Jean Barclay, Epilepsy Scotland Board	Alison McInnes, MSP
Matt Barclay, Community Pharmacy Scotland	Craig Miller, PA to R Simpson MSP
John Bevan, Observer	Nanette Milne MSP
Sheena Bevan, ESN & NHS Grampian Orkney & Shetland	Hilary Mounfield, Scottish Epilepsy Centre
Susan Duncan, Consultant	Caterina O'Connor, West of Scotland & Tayside Epilepsy MCN
Kenneth Gibson MSP	Gemma O'Hare, Scottish Epilepsy Initiative
Sian Hughes, MYSP	Allana Parker, Secretariat
Lorraine Kennedy (Observer)	PA to Roseanna Cunningham MSP
David Kerr, MYSP	Jennifer Simpson, Special Products
Claire Leonard, Epilepsy Connections	Richard Simpson MSP
Peter Martin, Observer	Anissa Tonberg, Epilepsy Scotland
Pamela Martis, NHS Lothian	Nicolas White, Quarriers
Linda McCaig, Observer	Sam Whitmore, Epilepsy Connections
Lesley McCallum, Scottish Epilepsy Initiative	Lesslie Young, Epilepsy Scotland

#### Apologies:

Eleanor Arthur, Southern General Hospital	Lorraine MacKenzie, Observer
Marilyn Bryce, Non MSP Individual Member	Duncan McNeil MSP
Graham Faulkner, Epilepsy Society	Maureen Swannie, Orkney Health and Care
Sarah Garland, The Daisy Garland	Sharon Wood, JEC
Jen Irvine, Kirklands Hospital	

1. Deputy Convenor Alison McInnes MSP welcomed guest speakers, MSYPs David Kerr and Sian Hughes and today's attendees to the first 2013 Cross Party Group on Epilepsy meeting.
2. Alison then briefly updated members on the Group's recent activities:
  - The draft note of the 27 September 2012 meeting was approved (following one query).
  - Since then, three parliamentary questions and three Members' motions arose concerning epilepsy. MSPs Jackie Baillie, Bob Dorris, Jim Hume, Aileen McLeod and Siobhan McMahon were involved in tabling issues, including how the Government supports people with epilepsy, epilepsy training in the licensed trade, Hemiplegia Awareness week, long-term conditions not exempted under previous prescription fees, the Scottish Health awards, Glasgow Epilepsy Genetics Service, and measures to assist patients waiting on a SPECT scan at Glasgow's Southern General Hospital. Alison thanked Group members for their regular activity in this area.
  - Three new members, Mark MacDonald, Chic Brodie and Anne McTaggart have joined. This Group just keeps growing and growing. John Park MSP retired as an MSP last December to take up a union post so stepped down from the Group. Many Cross Party Groups are on today so our membership is spread a bit thin, and Alison welcomed her fellow office bearers to the meeting.
  - Following the Group's discussion in September with the Public Health Minister, Michael Matheson MSP, the Convenor is writing to the Minister to ask what audit information is available for Scotland's social services.
  - The Group wants to find the number of unplanned admissions to A&E for people having seizures.

Especially those who are older and with complex needs because we think this will help identify possible cost savings through preventative care options and better seizure management.

- A site visit is going ahead between 11-1pm on Tuesday 14 May to the new Scottish Epilepsy Centre. The centre is based in Govan and the Secretariat will circulate details nearer the time.
  - Participants were asked to complete a short questionnaire and comments could be anonymous. The Epilepsy Consortium Scotland provides the secretariat for meetings and this feedback will help in planning future events.
  - International Purple Day which raises awareness of epilepsy is on Tuesday 26 March this year. All MSP's will be sent a purple ribbon to wear and a template press release to promote their support for Purple Day. Alison noted the awareness day's success last year with MSPs' local press coverage which is a good way forward.
  - National Epilepsy Week 2013 is from 19-25 May. Suggestions on the subject MSPs may debate can be sent to the secretariat. Convener Kenneth Gibson MSP has kindly offered to put down a Motion for that week. The Cross-Party Group on Mental Health will hold a joint meeting with ours from 1-2pm on Thursday 23 May. So lots of dates for the diary.
3. Alison McInnes MSP introduced guest speakers and members of the Scottish Youth Parliament, David Kerr and Sian Hughes. They talked about their epilepsy and involvement in the Scottish Youth Parliament's forthcoming campaign called 'Stamp out Stigma' for schools awareness of first aid and long term conditions and disabilities like epilepsy. Their key points covered:
- In 2010, both David and Sian were nominated by the Scottish Epilepsy Initiative's online forum (Tea Room) to become MSYPs. They regularly hold surgeries both online through the Tea Room with members and face to face at focus group meetings three times a year.
  - In 2012, they put forward a motion to MSYPs that learning about first aid and the effects of various disabilities and long term conditions should be made a compulsory part of the Personal Social Education curriculum. The motion was delivered with a quick fire epilepsy quiz to MSYPs.
  - The results were concerning; it was evident the majority of the Scottish Youth Parliament did not know what to do in the event of a seizure. Some MSYPs said they were unhappy with the quality of Personal Social Education they had received. Others commented that DVDs they were shown were unrelated to the topic, when they could be learning invaluable information and life skills.
  - Feedback from the young people David and Sian consulted revealed that young people with epilepsy felt they did not get the support they needed at school. Both staff and pupils did not have enough knowledge of epilepsy therefore young people did not feel confident that their peers would know what to do if they had a seizure. Pupils also experienced some bullying at school showing that there is still a stigma attached to condition and diagnosis of epilepsy.
  - The campaign will raise awareness of epilepsy and tackle social stigma in schools. The outcome of this campaign will be that secondary pupils feel confident in knowing what to do when someone had a seizure while a young person with epilepsy feels comfortable because fellow pupils will have this knowledge.
  - David and Sian are working with Scottish Epilepsy Initiative and Epilepsy Connections to create a block of lessons on epilepsy first aid, general information about epilepsy, and the issues that young people with epilepsy face. With the support of Education Scotland, interactive online lesson plans will be created in line with Curriculum for Excellence health and wellbeing outcomes, which teachers can easily adapt. A similar template to the "See Me" campaign and Asthma UK's "Two in every classroom campaign" will be used. These lesson plans will be available on Glow and also through Scottish Epilepsy Initiative's website. The MSYPs also hope to create a short film to go along with these lesson plans and have started blocking out ideas with a film student.

- By taking part, each school will pledge to stamp out the stigma associated with epilepsy. Alongside the lesson plans there is an online path of support. Each young person doing the activities will add their footprint to the 'stamp out stigma' awareness campaign. Everyone in schools and members of the public will be invited to join a 'foot print' photo campaign and pledge their support. The necessary resources are being produced for a campaign launch in August this year. David and Sian are hopeful that MSPs will support their campaign when it is launched, adding their own footprint to this path of support - stamping out stigma alongside them.
4. The Deputy Convener thanked David and Sian for their confident and informative presentation. She invited questions:

Hilary Mounfield offered both MSYPs her congratulations for doing something valuable and important. She commented that the strength of this proposal and the actions from it are amazing because it comes from young people with epilepsy. It is based on their direct experience which is being used to benefit other young people.

ESN Sheena Bevan congratulated the MSYPs again, mentioning that Professor Brodie and the whole staff at Scottish Epilepsy Initiative would be fiercely proud of them today. It took courage to come and explain about the campaign. She shared that the Tea Room was a really successful project. Scottish Epilepsy Initiative provides IT notepads for young people without computers so they can link to the Tea Room. Sheena covers NHS Orkney and Shetland and has assisted a number of young people there so they can link into the service. Many now feel it is a very special thing to be part of and it has brought them much closer together. She asked David to explain more about the project. He said the Tea Room is an online forum for young people aged between 13 and 19 with epilepsy. It offers a chance for them to share their experiences and help each other. It has a great social element to it as well as peer support.

Sian Hughes said having the support of Scottish Epilepsy Initiative's fieldworker/ Team Room moderator Gemma O'Hare has been vital. Knowing someone is there who will respond to an e-mail or a text message helped when she had decisions to make about a range of matters. Although Sian will be over the Tea Room age range soon, she hopes to stay on as a mentor for younger members. Having access to that network of people, spread all over the world now, was invaluable. Epilepsy is such a complex condition, and without this kind of support she didn't think many Tea Room users would be where they are now, getting their confidence back by sharing their life with online friends.

Alison McInnes MSP asked if the original motion put forward to Parliament to tackle schools awareness through the Personal Social Education curriculum should still become compulsory, given that David and Sian had taken voluntary steps to address it? David Kerr believed awareness of first aid should be compulsory because several long-term conditions are common in secondary schools including epilepsy, asthma, allergies, and diabetes. If pupils were armed with the knowledge of how to keep their friends stable if they have one of these conditions, the bottom line is they could end up saving a life – and you can't put a price on that.

Sian Hughes commented that tackling stigma through awareness raising is something that must be done and should become compulsory. She felt she had to leave a school because both staff and pupils were unaccepting of her epilepsy, did not understand the condition and weren't willing to be educated. As young people themselves, the MSYPs are best placed to educate others given their knowledge, experience and using feedback from other young people similarly affected by seizures.

Nanette Milne MSP agreed it was a hugely important issue. As Convenor of the Asthma Group, she was at a recent meeting regarding diabetes. An attendee with asthma was a teacher who shared that the one thing that terrified her throughout her teaching life was how to deal with a pupil with epilepsy in her class. She didn't have the confidence to do it. She would swap classes

with another teacher if epilepsy was an issue so he could help her pupils! By building up people's understanding we could have a generation of confident adults able to handle common issues.

Alison McInnes MSP invited epilepsy organisations to comment. Lesslie Young agreed that the evidence provided by the MSYPs was invaluable and wished them every success. Their talk demonstrated the need to cover this issue through teacher training. Providing an awareness of how to deal with epilepsy in the classroom, and the wider impact of epilepsy, would ensure that future generations were more comfortable and more able to deal with the condition. Epilepsy Scotland is in discussion with the GTC to look at that this very issue. It is a slow process; however, it is essential that this training is part of the curriculum when training teachers. The Deputy Convener invited Kenneth Gibson MSP to consider putting that on his list of things to think about. He responded that he was listening closely to all that had been said.

Sian Hughes mentioned she was fortunate to speak about epilepsy recently to a group of thirty student teachers who were coming to the end of their training. They found the information invaluable. Having little or no knowledge about epilepsy was something they were all worried about; what they would do if a seizure happened and who they would speak to for help. Gemma O'Hare agreed such awareness raising was totally valuable. When she did her teacher training, Epilepsy Scotland provided an awareness talk. It gave her so much more confidence to deal with this possibility in class; the benefit of such training stuck in her mind. Lesslie Young added that much of the work voluntary organisations do in schools is reactive not proactive. If epilepsy organisations could get in at the grass roots that would be much better.

Gerard Gahagan commended the MSYPS for their presentation. It illustrated the issues around stigma facing people with epilepsy. Quarriers' recent survey, reflected by the World Healthcare Organisation findings, showed stigma directly impacted quality of life more than the condition itself. With the new Epilepsy Consortium Scotland, the voluntary sector can work closely together but the resolution to stigma and raising awareness comes from additional services and support.

Richard Simpson MSP wondered if the British Heart Foundation model is worth considering. In his local school, pupils are being trained in CPR and additional life support systems. It has been hugely popular. Schools are given very good presentations and then get a certificate. Parents have been involved as well. Clare Leonard commented that their contact at Education Scotland assisting both Scottish Epilepsy Initiative and Epilepsy Connections with this project was also working with the British Heart Foundation to update their schools materials so a link was there.

5. The Deputy Convener thanked the MSYPs and suggested updating the Group another time about the campaign's progress and to see whether schools have taken it up. There was a quick update from organisations present:

Sheena Bevan, representing the Epilepsy Specialist Nurse Association and also from NHS Grampian mentioned that Napier University is working in conjunction Euro Education and Epilepsy Action to develop post graduate teaching in relation to epilepsy. The distance learning course covers MS and Parkinson's disease and will be rolled out this summer. NHS Grampian started another Epilepsy Specialist Nurse in December (23 hours a week). The post is funded by Epilepsy Action for two years then NHS Grampian will fund it.

Epilepsy nurses are concerned about the downgrading from band 7 for specialist posts to save health boards' money. This downgrading will impact their career pathway for specialist nurses across the board. A Parliamentary Question on this may be raised in due course.

A mini conference for Shetland (17 April) is being arranged, with GP's medical nursing staff and staff allied to health attending. On 16 April there will be an open information meeting on the island. A similar conference was held in Orkney last year, as part of a two year project run by Sheena Bevan. Scottish Epilepsy Initiative has funded both conferences. Nanette Milne MSP thanked Sheena Bevan for these positive updates. As a North East representative she was glad to hear NHS Grampian has another ESN post, having written to the health board for a long time.

Gerard Gahagan announced that the new national epilepsy centre will be complete in early February with the service fully operational from 15 April. He thanked the Scottish government and the NHS for their support. This true partnership approach in developing a national provision will benefit people now and for future generations. He welcomed the impending visit by the Group to this impressive facility that is available for Scotland.

Lesslie Young outlined progress with various legal system initiatives, including training advocates about the effects of epilepsy when representing serious and minor crimes. The work has expanded into awareness training with the licence trade. She also mentioned the development and delivery of a new primary care course in Argyll & Bute which is now being expanded for use in other areas. A novel project in Dumfries & Galloway which comprises three partners from three different sectors working together to provide a local epilepsy service that wasn't there is being re-assessed. Health Improvement Scotland is involved to consider baseline auditing practices and service pathways. Epilepsy Scotland is launching its Employer of the year award with the Cabinet Secretary for Health and Wellbeing presenting the awards at the end of April.

Sam Whitmore commented on the pressure facing Epilepsy Connections' Fieldwork Team to manage people constantly calling and asking for support in relation to changes in benefits.

Alison McInnes MSP then mentioned taking forward awareness-raising in schools to include asthma, diabetes and similar long-term conditions and disabilities in a Members debate. Kenneth Gibson MSP agreed it would be good to broaden it out and get a really well attended Members debate with epilepsy very much at the forefront but also to bring in other conditions as well. The Group wants to build support within the Parliament for the stamp out stigma campaign and hopefully get a positive response from the Scottish Government. He thought the new Scottish Epilepsy Centre will be a real boost to Scottish services and looked forward to the upcoming visit. He reminded organisations who are members of this Cross Party Group to feel free to contact any MSP in the Cross Party Group if they wanted things discussed or taken forward, including letters to ministers, motions and parliamentary questions. It was important to keep epilepsy at the forefront of the Scottish Government's thinking. This is an issue that is never going to go away so services need to continually improve along with education to tell people what epilepsy is all about. Support needs to be enhanced and the Group can ensure the condition retains a high profile. It is a tribute to all the hard work of the organisations around the table that out of seventy two Cross Party Groups it has the highest MSP membership and to continue to build the momentum.

Nanette Milne MSP commented that in the other Cross Party Groups, the issue of transitional care for young people being diagnosed between primary school and secondary school, and having to cope with their condition once they become teenagers is perhaps an area where there can be some joint involvement between the organisations present.

The Deputy Convener thanked everyone for attending and completing their evaluation forms. The date of the next meeting and AGM is Thursday 25 April in Committee Room 2 at 1pm. The speaker will be Dr Richard Chin, the Clinical Senior Lecturer and Director of the Muir Maxwell Epilepsy Centre, to discuss epilepsy research.