

DRAFT Note of Meeting – Cross- Party Group on Epilepsy, 30 April 2015

In Attendance:

Jean Alcock - Epilepsy Connections	Allana Parker - ECS Secretariat
Jean Barclay – Observer	Kamlash Parmar – Eisai
Celia Brand - Epilepsy Nurse Consultant, NHS Lothian	Derek Robertson – Epilepsy Liaison Nurse, NHS Lothian
Kenneth Gibson MSP	Karyn Robertson – Scottish Paediatric Epilepsy Network
John Heaney - West Dunbartonshire Epilepsy Support Group	Brian Rocks - West Dunbartonshire Epilepsy Support Group
Fiona Hughes - Clinical Nurse Specialist Epilepsy, Fife	Anna Smaill – Muir Maxwell Trust
Christine Jeans - SUDEP Action Scotland	Jacqui Telfer - Epilepsy Scotland
Ann Maxwell – Muir Maxwell Trust	John Thomson - Observer
Hilary Mounfield - Scottish Epilepsy Centre	Jean Urquhart MSP

Apologies:

Cameron Buchanan MSP	Nanette Milne MSP
Jo Campbell, ESN Aberdeen	Eileen McGubbin – ESN , NHS Ayrshire and Arran
Gerard Gahagan – Quarriers	Mary Nicol - Observer
Jen Irvine, ESN	Jane Stuart – NHS Lothian
Alison McInnes MSP	Sam Whitmore – Epilepsy Connections
Helen Macdonald – Lanarkshire Epilepsy Support Group	Lesslie Young, Epilepsy Scotland
Paul Martin - Observer	

1. Convener Kenneth Gibson MSP welcomed attendees to the meeting and AGM.
2. He gave a short update: no changes to the circulated January 2015 draft note, it was approved.
 - Since January there had been two Members Motions for International Purple Day by MSPs Gil Paterson and Mark McDonald, collectively signed by 72 MSPs (full details in the AGM pack)
 - Jamie Hepburn, the Minister for Sport, Health Improvement and Mental Health has written to say that while he cannot speak at today’s AGM due to a heavily committed diary, he is keen to attend a future meeting of the Cross-Party Group. The Secretariat will arrange a date for his diary
 - 68 MSPs helped to raise awareness of Purple Day on 26 March. Many were either wearing the colour associated with epilepsy or wore a purple ribbon or badge in Parliament. Others tweeted the Purple Day hashtag or sent photos and a press release to their local media
 - This Group is taking forward a Freedom of Information request to find out more about EEG location and provision in Scotland. MSPs want to know its data transfer capability, existing levels of technician neurophysiologists, and current waiting times for accessing routine and acute EEGs. The Convener will keep you informed of progress with this issue
 - The Epilepsy Consortium Scotland (ECS) intends to offer short epilepsy awareness training sessions, lasting 30 minutes to MSPs and parliamentary staff. These will be available on Wednesday 20 and Thursday 21 May during National Epilepsy Week. Details will be circulated by the Secretariat.
 - Please can people 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 2014. However, the Epilepsy Consortium Scotland (ECS) has provided assistance through a Secretariat worth £679 and has met the administration costs for mailing, briefings, catering, travel and speakers' expenses amounting to £695.49 for the Epilepsy Group meetings in the last 12 months (April and September 2014 and January 2015).
 - **Nomination and Election of Officers** –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 Jean Urquhart MSP
 - Alison McInnes was re-elected as Deputy Convener, proposed by Jean Urquhart MSP and seconded by Kenneth Gibson MSP
 - Richard Simpson was re-elected as Deputy Convener, proposed by Jean Urquhart MSP and seconded by Kenneth Gibson MSP
 - Nanette Milne MSP was re-elected as Secretary, proposed by Jean Urquhart and seconded by Kenneth Gibson MSP
4. MSPs present agreed that Epilepsy Scotland continues to provide the Secretariat on behalf of the Epilepsy Consortium Scotland. The Convener thanked everyone for their valued support and contribution to the meetings
5. The Convener introduced guest speaker Ann Maxwell. As co-founder of the Muir Maxwell Trust (MMT), Ann shared an overview of the work it does:
- The Muir Maxwell Trust, set up 12 years ago by Ann and her husband Jonny who chairs it, has a remit to provide practical support to children struggling with epilepsy, and to their families. Although Scottish registered and based in Musselburgh, the Trust provides support across the whole of the UK and in Ireland. It is a small and impressive organisation with 14 trustees (a mix of business professionals and parents of children with epilepsy) and two paid staff. Ann is a full time volunteer fundraiser. Since 2003, MMT has raised over £8 million
 - The focus for MMT is childhood epilepsy and it also creates an awareness of the impact of complex childhood epilepsy. The Trust is named after Muir, one of Jonny and Ann's three sons, who had his first seizure when he was four months old. It was the start of a journey that altered their lives. A number of years later, Muir was diagnosed with Dravet Syndrome, which is one of the most severe epilepsies
 - From the age of five, Muir attended a special school, Donaldson's in Linlithgow. He became a resident when he was 12 and comes home at the weekend. Now aged 18, Muir is profoundly brain damaged as a consequence of his epilepsy so he can't read, he can't write and can barely colour in between the lines. As an adult, he will never work, marry or have children. He needs 24/7 care which includes his personal care. Yet Muir is very happy, he is a phenomenal young man with a great sense of humour and personality
 - Ann emphasised how epilepsy can range from being well controlled to intractable. She pointed out it is dramatically different to deal with severe and complex epilepsy. There are multiple seizure types often with early onset in infancy. There can be an underlying genetic syndrome, leading to profound and multiple learning disabilities at a later stage, such as autism, dyspraxia, ADHD, speech and language problems and challenging behaviour. Though not in Muir's case, some of the children the Trust looks after can be incontinent, tube fed and have poor mobility
 - The Trust mainly aids children up to the age of 21. Around half of 120,000 children in the UK aged under 21 will have uncontrolled seizures, and like Muir, 20,000 have severe and complex epilepsy. On average, one in 200 children will develop epilepsy. Some can succumb to SUDEP (Sudden and Unexplained Death in Epilepsy) but for severe and complex epilepsy, the risk of SUDEP is greater
 - MMT's first project was the distribution of epilepsy alarms. It aimed to help families cope with the strain of worrying about seizures during the night and the possible risk of death. There was no advertising and demand was manageable. To date 3,000 epilepsy alarms retailing at £740 each have been distributed. The Trust pays £500 for an alarm, an amount most applicants can't afford. Now there is a permanent waiting list of 300 families and more are being turned away daily. Over

the last decade, MMT has also been very involved in the manufacture/improvement of epilepsy alarms and has contributed to emergent new technology

- Some good things are happening in epilepsy to which MMT has contributed in the last ten years, especially in the area of diagnostics. A 2007 MMT fundraising ball in London paid for nine state of the art video telemetry units for UK hospitals. These included The Sick Children's in Edinburgh and Glasgow's Yorkhill hospital, as well as to the national charity Young Epilepsy which named its video telemetry wing after Muir Maxwell. Similar portable technology was purchased to enable patients to be monitored at home for EEGs.

Genetic testing in Australia of Muir's DNA resulted in a two year wait and positive diagnosis of a mutation in Muir's SCN1a gene known as Dravet Syndrome. Consultant paediatricians subsequently invited Ann to help establish a Genetic Diagnostic Service dedicated to children with epilepsy, based in Yorkhill Hospital. MMT purchased the first DNA Sequencer in the UK dedicated to testing DNA from children with suspected epilepsies. It has went on to be an award winning and government self-funded service. The Trust initially funded a Fellow. He worked with families receiving a genetic diagnosis for their child and he published a number of significant papers. These addressed serious quality of life issues which families struggle to deal with at the severe and complex end of the spectrum. MMT is proud of what this service achieves

- Last year, MMT was able to contribute to improving MRI imaging that helps with epilepsy surgery in a pioneering initiative happening in the UK. Ann recently got involved in a UK campaign to trial medical marijuana for children with very profound epilepsies. Fellow MMT colleague, consultant neurologist Richard Chin worked directly with MHRA/Ethics team to enable that research to happen. He also heads up the collaborative partnership work between the Muir Maxwell Epilepsy Centre and the University of Edinburgh's Neuro-sciences Centre, focusing on the causes, cures and real quality of life issues around epilepsy
- MMT's remit is shifting now Muir has reached 18. Therefore, the work of the Trust and its campaigning is about supporting young people with profound and multiple learning disabilities who are leaving school and transitioning to adult services. What is delivered in children's services is not necessarily matched in adult care, which is a concern
- MMT has received considerable support, ranging from Princess Ann as Chancellor of the University of Edinburgh, from David Cameron in Westminster and Shona Robison in the Scottish Government. Celebrities such as Christopher Biggins help raise awareness and increase MMT's fundraising profile which in turn attracts a strong and loyal supporter base from the business sector. Today MMT launches its new Cupcake Challenge campaign to raise awareness of epilepsy (with online Just Giving donations, by phone to MMTC8870070, and trending on twitter with #beatepilepsy.) Someone once said to Ann that "beating epilepsy should be a piece of cake". MMT's Cupcake campaign hopes to become an international challenge that creates a new Guinness World Record and changes perceptions of epilepsy worldwide.

6. The Convener thanked Ann Maxwell for her presentation and invited questions:

Jean Urquhart MSP asked if other hospitals in the UK had developed diagnostic testing or undertaken research similar to that by Dr Richard Chin. Ann Maxwell said the Genetic Diagnostic Service at Yorkhill fulfils the needs of the whole of the UK at the moment, receiving DNA from the rest of the UK where genetic epilepsies are suspected. Great Ormond Street Hospital also has its own genetic testing which is equally sophisticated. The national cohort data held at Yorkhill is more extensive, enabling on-going research by MMT's Fellow who has produced at least five published papers. Genetic testing is now accepted and recognised alongside clinical diagnosis.

Allana Parker asked about MMT's schools awareness-raising programme. Ann Maxwell replied her 'Mum on the run' campaign involved speaking to children about the basics of epilepsy and the work of MMT. Her presentation had been well received with pupils coming in with their heads down and going out with their heads up, inspired because of what they heard about Muir Maxwell. The schools programme is not being actively marketed given the new Cupcake campaign.

Brian Rocks wondered if the alarms were purchased for every area in Scotland as well as the UK? Ann said sometimes epilepsy specialist nurses approached MMT on behalf of families or else families applied directly from all over the country. MMT staff will send a voucher to enable families to claim their epilepsy alarm, currently from Sentorium in Fife. MMT regularly reviews and tests different kind of alarms.

John Heaney mentioned that alarms for adults with epilepsy are available from social work for a monthly fee. He asked if MMT offered this? Ann explained it was much easier for adults to get an epilepsy alarm from social services. Over the past 12 years she had discussed who will fund epilepsy alarms with the Procurement team in the Scottish Government Tele care Department, the Minister for Health, social workers and epilepsy specialist nurse. Convener Kenneth Gibson MSP is now helping with a potential motion to be discussed in Parliament given that there are a handful of people who have achieved getting an alarm but the UK wide majority don't get one. Alarms tend to be directed towards old people first who have epilepsy and dementia. In fact, the Cupcake campaign is fundraising specifically to raise a minimum of £250,000 to provide 500 epilepsy alarms. MMT is going to challenge the Scottish Government and Westminster to match fund on every pound raised so this issue can be addressed once and for all.

Celia Brand relayed some good news about the Community Alarm Services (CAS). Many in Scotland now provide for children and families who fill in the appropriate referral forms. However, CAS can be difficult to find, they are not well advertised but when asked directly for help, no request has been turned down yet. There are councils where locating CAS is more difficult but if people can get the referral form they'll get the alarm. Ann Maxwell felt the point was it should not be difficult. Celia Brand mentioned only a few local authorities said they would not provide, and Forth Valley will not give an alarm to anyone aged under 18 unless it's a specific circumstance.

John Heaney mentioned occupational therapist assessments of health and care needs for people with epilepsy. In terms of clinical governance, Celia Brand wanted to see Community Alarm Services maintaining data on alarms to ensure they are working properly. She suggested the CPG on Epilepsy needed to push this idea forward with local authorities and the local numbers eligible for CAS would not be huge. Ann Maxwell reminded everyone of the 300 families on the MMT waiting list and having to turn away new applicants daily. Celia Brand suggested MMT refer these families to ESNs as there may be other reasons involved. Ann Maxwell said that was their practice but some families kept coming back, though hearing of CAS provision was good news.

Chris Jeans commented that the MMT's provision of alarms was fantastic and so important. She learned retrospectively about alarms and similar devices after her son Steven died suddenly from epilepsy (SUDEP) over four years ago. If she had known about these alarms at the time, she would have got one. Celia Brand said that these alarms are not a preventer of sudden and unexpected death. Chris Jeans agreed but explained for a mum of a child or a family member with epilepsy she could guarantee that people would want to use everything available to try and prevent SUDEP. Celia Brand explained that alarms pick up convulsions rather than seizure types. Interesting published research had described a man who died in a video telemetry unit while he was being monitored. He took a fatal simple partial seizure in his sleep which wasn't picked up by the bed alarm. It was important to develop alarms that detected more than just movements.

Ann Maxwell offered the view that alarms helped a family's quality of life and peace of mind. The idea that a child has a seizure, while the parents sleep through it, is truly distressing. Her son Muir had slept in his parents' bed night after night until they got an epilepsy alarm. Families may decide to sleep in the same room, or parents don't sleep together anymore when a child has such severe epilepsy. Celia Brand mentioned a recent research study in the North East of Scotland which looked at alarms and usage. Lots of parents chose listening devices and newer alarms with video screens over a bed alarm that only detects movement or wetness. Ann Maxwell remarked that some alarms are now starting to monitor the person's heart rate as well. Brian Rocks concurred as the alarm he is testing for West Dunbartonshire Council measures pulse and heart rate and it can tell different types of seizure. Ann Maxwell mentioned that current alarms will be like dinosaurs compared to the technology that's coming. Yet perhaps the value placed by families on alarms hasn't necessarily been recognised in quite the same way by the medical profession and Government.

7. Kenneth Gibson thanked Ann for answering these questions. He invited organisations to bring any other points to the attention of the group.

Hilary Mounfield said that for National Epilepsy Week, the William Quarriers Scottish Epilepsy Centre is going to privately screen a film called 'Electricity' on Wednesday 20 May. It is a commercial film which was similarly shown in Glasgow by Quarriers a few months ago. It features a young woman who has epilepsy and she gives a very realistic representation. Anyone who would like to come along to the May event can get in touch with Quarriers' staff.

John Heaney mentioned his West Dunbartonshire support group recently completed 12 epilepsy awareness training sessions with local police officers and fire fighters. An Open Day is being planned at Clydebank Fire Station on 20 May. Jean Urquhart MSP asked if the secretariat would circulate these details of National Epilepsy Week events to MSPs on the Group.

8. Future parliamentary opportunities include:

- MSPs can get information and plan their activities for National Epilepsy Week by visiting the Epilepsy Consortium Scotland exhibition in the Garden Lobby from 19-21 May
- New SIGN guidance for adults with epilepsy will be launched on 18 June. MSPs can take part in a Signing photo call, on Thursday 21 May directly after First Minister's Question Time. They will have the cover if not the whole new guidance to sign and wave in the air.

9. Date of next meeting – this will be Thursday 24 September at the usual time 1-2pm. There will only be one further meeting on 28 January 2016 before the next Scottish Parliament elections.

10. Please remember to sent your ideas for possible topics for the next meeting to the Secretariat. The office bearers will consider these during recess.