

**DRAFT Note of Meeting – Cross Party Group on Epilepsy, 26 September 2013**

**In Attendance:**

Nadine Aliane, Diversity Unit, Police Scotland	Caterina O'Connor, West of Scotland & Tayside Epilepsy MCN
Guy Armstrong, UCB Pharma	Allana Parker, Secretariat
Jean Barclay, Epilepsy Scotland Board	Dr Carol Page, Consultant psychiatrist, Lynebank Hospital Dunfermline
Cathy Dorrian, Scottish Centre for Telehealth & Telecare	Megan Sabbah, PA to Kenneth Gibson MSP
Helen Eadie MSP	Jennifer Simpson, Special Products
Kenneth Gibson MSP	Anissa Tonberg, Epilepsy Scotland
Janet Henderson, New Directions, West Lothian	Murray Tyrrell, Observer
Andrena Hughes, Observer	Jean Urquhart MSP
Pam Martis, NHS Lothian	Gertie Wallace, Fiscal Depute COPFS
Graeme Mitchell, i6 Programme Police Scotland	Lesslie Young, Epilepsy Scotland
Paul Mullan, Quarriers	

Celia Brand, Paediatric Epilepsy Nurse Consultant	Hilary Mounfield, Scottish Epilepsy Centre
Matt Barclay, Community Pharmacy	Alison McInnes MSP
Marilyn Bryce, Non MSP Individual Member	Gemma O'Hare, Scottish Epilepsy Initiative
Jo Campbell, ESN Aberdeen	Kristin Pagano, Viropharma
Hugh Henry MSP	Linda Radcliffe, ESN LD Glasgow
Jane Holmes, Observer	Richard Simpson MSP
Kevin Kelly, ESN Glasgow	Pauline Smith, ESN Dundee
Karen Lawrence, ESN Tayside	Michele Thorpe, NHS Lothian
Claire Leonard, Epilepsy Connections	Lauren Todd, Eisai
Lorraine Mackenzie	John Toland, ESN Dunfermline
Peter Martin, Observer	Margaret Wilson, ESN Yorkhill
Anne Maxwell, Muir Maxwell Trust	Tom Wilson, Hansel Village
Claire Miller, Observer	Susan Yule, ESN Glasgow
Nanette Milne MSP	

**Apologies:**

1. Convenor Kenneth Gibson MSP welcomed attendees to the meeting and gave an update on what's been happening since the last meeting in April.
2. First, the draft note of the April 2013 meeting was approved.
  - On 14 May, the Group used the opportunity to visit the new Scottish Epilepsy Centre. It is a remarkable building and a flagship service for the whole of Scotland.
  - A joint meeting was held on 23 May with the Mental Health Cross Party Group. The discussion featured drug management and access to support services. All speakers were outstanding and spoke from the heart. Both conveners, Kenneth Gibson and Malcolm Chisholm agreed there may be future opportunities for these Groups to work together on joint issues.
  - The Minister for Public Health Michael Matheson has responded to some issues that were raised before recess. There was a general reply about the audit process for social work services.
  - When the Convener wrote asking Mr Matheson to consider how Epilepsy 12's extended audit of Scottish paediatric services could be funded, he received a supportive response overall. This

CPG acknowledges the Scottish Paediatric Epilepsy Network for its successful bid to National Services Scotland. Copies of these ministerial responses are available to read and take away.

- Since April there have been four member's motions mentioning epilepsy. These were put by MSPs Siobhan McMahon, Jackie Baillie and Kenneth Gibson.
  - The Epilepsy Consortium Scotland (ECS) held its Garden Lobby exhibition in May to promote National Epilepsy Week. Since then six MSPs have joined or re-joined this Cross-Party Group including: James Dornan, Jayne Baxter, Angus MacDonald, Gordon MacDonald, Mark McDonald and Margaret McDougall (making 33 members).
  - The Convener plans to secure cross-party support for a forthcoming Members debate to highlight the launch of the Stamp out Stigma campaign for schools. 22 local authorities have now provided details about first aid and epilepsy awareness training in local schools. Reminder letters have been sent to the remainder of councils. Having these facts will help to inform a future Members debate, as will the schools training information supplied by Consortium members.
  - Everyone should have been given an evaluation sheet for today's meeting. Please take a few moments to complete it.
3. The Convener introduced three guest speakers, Nadine Aliane from Police Scotland's Diversity Unit, Inspector Graeme Mitchell with Police Scotland's i6 Programme, and Gertie Wallace, Deputy Head of Policy Division with the Crown Office Procurator and Fiscal Service (COPFS)

**Nadine Aliane** outlined Police Scotland's National Safer Communities Department's role in dealing with equality and diversity issues. Current legislation covers someone who is the victim of hate crime either because of their epilepsy or perceived epilepsy or any other disability. This type of offence may lend itself to a heavier penalty by courts

- Police Scotland recognises that hate crime generally is under-reported including disabled related hate crime, which includes people with epilepsy. Reasons for the under-reporting of hate crime can include people feeling the incident is not serious enough to report or not having the confidence to make a report
- Part of Police Scotland's national equality and diversity outcomes include helping people to get a better understanding of hate crime and recognise it when it happens. Those who are actually being victimised or harassed need to know such behaviour is against the law and they can report instances to the police. Different means and methods are being considered to address this so that designated cross-protected groups, including the epilepsy community, can confidently engage with Police Scotland. If anyone with epilepsy is either a victim or witness to a crime and needs assistance, they can report it and not necessarily at a police station
- As part of an over-arching strategy to keep people safe in their community, Police Scotland and the Crown Office set up a Criminal Justice Disability Project in May 2013 that involves various organisations across the whole criminal justice sector. It hopes to tackle some of the issues raised in a recent Capability Scotland report
- Some common themes are emerging. These include making changes in police and legislative procedures and rules for dealing with people from the disabled community. Having external education will also raise public awareness of how to assist people who have epilepsy with dignity and respect. Internal education for staff would be helpful to improve customer service
- There is a standard procedure nationally for third party reporting of hate crime incidents. This covers remote reporting in around 260 sites in Scotland where people can go to designated places and organisations out with a police station (e.g. a school, council office, community group). They can talk in confidence with individuals trained by the police to take reports. These reports can then be referred to Police Scotland. A roll out of sites in more outlying areas is likely
- A new DVD planned with Epilepsy Scotland will link the epilepsy awareness training which all officers get as part of their first aid course. The content of the course is also being updated.

**Graeme Mitchell** then explained that the i6 programme will provide Police Scotland with a single computerised source for information. Data covers crimes, custody and criminal justice cases to missing property, missing and vulnerable persons or adults at risk

- The i6 programme standardises the database structure of eight former police forces. It will provide a holistic view of any individual in the database structure and link incidents in which they are involved and where they are potentially a victim
- Having common standards in recording data brings uniformity and a consistency in how officers are trained to deal with individuals who have epilepsy. If a person states they have an underlying medical condition such as epilepsy, or it is disclosed through a medical examination or the attendance of medical staff, it can be recorded
- Medical markers can identify if the person is vulnerable or at risk due to their condition, for example, if the individual had committed an offence and was put into the crime/custody suite
- Flagging records involving hate crime and putting medical markers for conditions like epilepsy on the system will drive procedural guidance and help officers to do their job. It will allow contextual help to be given to officers to deal with cases and standardise statistical performance reporting
- The i6 system brings a clearer chronology and depth of information about individuals. This helps informed decision making, not only as a police service but also when sharing information in a multi agency environment with social work, health, education or any third party organisation

**Gertie Wallace** commended the CPG on Epilepsy and Epilepsy Scotland for bringing an important issue to the attention of the Lord Advocate. Individuals with epilepsy had been taken to court only for the case to be later dropped essentially because the person's actions had occurred due to a seizure. This could bring devastating consequences to their personal and working lives and did not serve anyone in the justice system. In 2010, the Epilepsy and the Law working group brought COPFS, other criminal justice partners and professionals like Professor Bone together

- At that time there was recognition of a lack of training and information on epilepsy available for COPFS and staff. If the police are aware of medical issues, they provide that information in the first part of a prosecution report regarding the history of the accused. How prosecutors deal with it is a different issue
- Epilepsy Scotland has given annual input training to procurator fiscal deputes at the outset of their careers. It forms part of a legal module covering the context of decision making (called case marking). It reminds staff they need to be aware of the many features of medical conditions
- Epilepsy is a good starting point for a process that considers other issues than just a set of facts. The training video used shows someone whose behaviour during and after a seizure looks as if it is initiated by drink or drugs. This is clearly a feature which the police come across daily. Asking the right questions at that point is important to gain the right information. In turn this suggests the kind of information required for the report on individuals if they enter the criminal justice system
- There is also training for advocate deputes as senior prosecutors in the High Court. They often deal with more serious cases. To ensure good use of resources in taking cases through the high court judiciary, it is crucial to get the right information, and here that would be from medical professionals regarding seizure behaviours and causes. In one such case, the result was directly affected by information and advice from Epilepsy Scotland, which is a very useful resource for COPFS
- In lower level offences, decisions about possible prosecution involving epilepsy can be easier to make if good information is provided and may result in the case not being taken further
- Substantial changes to the COPFS structure has led to federation working across three main geographical areas, with case marking carried out by a separate team who will build up a specialism. The same process happens for court work and preparation of more serious cases. Case marking is crucial when initial decisions about the case are being made. If case markers know what to look for regarding epilepsy they may be able to instruct further enquiries before a crucial decision is made about whether a case is going to court or not
- COPFS has also set up specialist divisions and that includes the Scottish Fatalities Investigation Unit. There have been a number of FAI's involving sudden and unexpected deaths from epilepsy

(SUDEP). Part of this Unit's remit is to provide advice and support to those Procurator Fiscals who investigate SUDEP and to have strict control over the time limits in which FAIs are held which help families

- COPFS has published equality outcomes. People of any background or disability will be treated with respect and be given the proper support when reporting matters to the police or coming into contact with the criminal justice system. Disability hate crime is vastly unreported. Till 2013 only 138 charges were reported with aggravation and prejudice related to disability (it doubled from 2012) compared with thousands of charges related to racial aggravation. Ninety (65%) of these reported disability hate crime incidents led to court proceedings
- The proposed training DVD and supporting materials prepared by Epilepsy Scotland will be disseminated to all staff to raise epilepsy awareness. This is a good outcome of partnership working which supports best practice throughout the system to help officers deal with cases
- Access to justice means training staff to give appropriate support to victims, vulnerable witnesses and the accused as they go through the court service. Our quality champion Ruth McQuade leads the Justice Quality sub group under which the disability working group has been set up
- The IT system can also flag details of vulnerable witnesses. Our Victim Information Advice service can be in contact and make sure the right supports are ready to assist them in coming to court to give evidence and throughout the process itself
- While COPFS needs information from the police to make sure it can do the proper work, all those involved in the justice system and judiciary must have an awareness of epilepsy and how it may impact a person's ability to engage with the process. It is important that we all understand what the issues are so there is confidence in the justice system and correct decisions are taken early.

4. The Convener thanked the speakers for their contribution and asked for questions:

Caterina O'Connor questioned where people with epilepsy can do third party reporting and also asked if the Epilepsy Consortium Scotland should look at the issue of developing places across Scotland? Nadine Aliane mentioned a recent scoping exercise on 260 sites across Scotland, which were at different stages of development. Some required refresher training. Details of all sites will appear on Police Scotland's website. A new best practice training package in third party reporting will be delivered by designated officers through community involvement. Gaps for new sites can be identified and not solely for people with epilepsy. Groups represented here could decide to offer the service, their staff would be trained by Police Scotland and their new reporting site could be marketed. Police Scotland is striving to get more sites that are specific for the disabled community such as CABs, council tax and housing offices. The aim is to include sites where people normally go about their daily life and not necessarily go to a specific epilepsy site.

Lesslie Young added that Epilepsy Scotland was having third party training in October for the Helpline and contact team and also support workers.

Murray Tyrell mentioned that in his experience it was more likely that those who suffer from confusion after a seizure could sometimes face legal consequences. His example would be taking a seizure in the street, walking into a shop, picking up an item and walking out again. The shopkeeper might then call the police. The officer may be heavy handed because he doesn't know the person has epilepsy and thinks he is faced with a real criminal. The police should be able to identify somebody who is in a state of confusion, and save an unnecessarily visit to the police station. He thought epilepsy-related crimes to reach the high court would be relatively few. Gertie Wallace agreed it was more common for people with epilepsy to be victims or witnesses coming into the system than being accused of crimes. So it is important to recognise that confused state and when a case gets to the fiscal's desk they consider if something is not right.

Lesslie Young gave a real life incident where the police were called to a shop lifting incident in Glasgow. The officer attending had epilepsy awareness training. He recognised the person who had been accused of shoplifting didn't fit the bill. After asking several questions, the case went no further. The officer freely admitted that had he not had the training, that person would have been taken to the police station. Officers have to content with a lot of factors including someone being

overly aggressive in a seizure and they need to avoid any injury. Being able to have as much information as possible allows the officer to make an informed decision which would be helpful. Nadine Aliane agreed that training will help officers preserve the dignity and respect of people they are called to assist, and this would lead to less complaints.

Anissa Tonberg mentioned that cases involving difficult epilepsy can often go hand in hand with a learning disability. She asked what is happening with defining the role of the appropriate adult given Police Scotland's work involving witnesses and vulnerable suspects. The Convener mentioned this issue was still going through the Scottish Parliament and Graeme Mitchell agreed that the appropriate adult role has not yet been absolutely decided. He believed the tack taken when interviewing someone with a learning disability was to err on the side of caution. Officers would consider any factors that impair an individual and their ability to make appropriate choices or to give the appropriate information. They would engage the services of the appropriate adult or seek further guidance on this to make sure that the individual understands what their rights are.

Cathy Dorrian updated the Group on her novel telemedicine project with the Scottish Prison Service. The responsibility for prison health care has now been moved back to the NHS. Along with Dundee neurologist Dr Morrison, she is looking at installing equipment to conduct medication reviews of the prison population in Perth. The Police Scotland Custody Division have installed video conferencing into Fraserburgh custody suite. Scottish Centre for Telehealth & Telecare staff have trained custody staff to take temperatures, blood pressure and soon blood glucose as well for patients with conditions like epilepsy or those suffering drug or alcohol withdrawal symptoms. There is a link from the custody sergeant and their staff to a local hospital. They can access specialist nurses to assess the patient and consider whether they need any medication or care to reduce any patient risk. This innovative service provides support to officers and prisoners. There may be a potential cross-over around the electronic patient record and emergency care solving for people with epilepsy and Police Scotland's i6.

Kenneth Gibson MSP inquired if there could be one Police Scotland information number that people could contact that would deal with epilepsy and criminal justice system reporting? Nadine Aliane said it was a great idea but then other groups would also want their own single number. There is the national 101 number, although not specifically for the disabled community. Mr Gibson asked if the caller could be referred to somebody who has a specialism in for example epilepsy? Nadine Aliane responded that any hate crime would be treated extremely seriously and as a matter of urgency especially if it's an on-going situation. In terms of third party reporting, on-line reporting is available on the internet. Graeme Mitchell agreed that telephone calls and online information on hate crime are fast tracked through Police Scotland systems. Allana Parker mentioned the Epilepsy Consortium Scotland would be interested to list sites for third reporting.

5. The Convener thanked everyone for their attendance and contributions.
6. **The next Cross Party Group for Epilepsy meeting will be held on Thursday 30<sup>th</sup> January 2014, in Committee Room 2.**