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**Note of Meeting – Cross- Party Group on Epilepsy, 1 October 2020**

Held virtually via Zoom

**In Attendance:**

Alan Guild	Alasdair Allan MSP
Anissa Tonberg, Epilepsy Scotland	Anne Greenall
Catriona Jamieson, PAMIS	Chris Jeans, SUDEP Action
Celia Brand, NHS Lothian	Colleen Wilson, Epilepsy Connections
Christian Schnier	Emily Ord, Eisai Ltd
Elaine Collard, NHS Highland	Jan Campbell, UCB Pharma
Gillian Smith, University Glasgow	Jane Stuart, NHS Lothian
Jane Holmes	Jeremy Balfour MSP
Jay Shetty, NHS Lothian	John Bruce
Joan McAlpine MSP	Jude Kilbee, Bial Pharma
John Thomson, Eisai Ltd	Kerry Thompson
Kenelma McCrae	Lorraine Mackenzie
Lesslie Young, Epilepsy Scotland	Norma Crawford, Quarriers
Martin McCulloch	Paul Gillon, Veriton Pharma
Pat Graham	Richard Chin, NHS Lothian
Rebecca Marshall, Mindroom	Shirley Maxwell, Epilepsy Connections
Rona Johnson, Epilepsy Scotland	Sylvia Lawrie
Shona Cardle, Glasgow Children's Hospital Charity	

**Apologies:**

Kenneth Gibson MSP	Ailsa McClellan, NHS Lothian
Rachel Lloyd, NHS Lothian	John Toland, NHS Fife

1. Convener Alasdair Allan MSP welcomed attendees to today's Meeting and gave an update since the last meeting in February:
  - Epidyolex, a new cannabis-based drug has been approved by the Scottish Medicines Council (SMC) as a treatment option for two severe epilepsy syndromes, Lennox Gastaut and Dravet Syndrome.
  - A new patient and carer recorded video service, called VCreateNeuro, has been launched in some health boards to aid the diagnosis and management of epilepsy. Patients and carers can quickly and securely share videos of seizures to their doctor or nurse.
  - The Cumberlege report was published which details the ways in which people have suffered avoidable harm through Primodos, pelvic mesh and sodium valproate. The Scottish Government are assessing how they can implement the recommendations and are actively considering a sodium valproate registry.
  - Epilepsy Scotland and the Dumfries and Galloway health board have been working together to bring paediatric epilepsy specialist nursing support to the area. Sarah Gemmell has now taken up the role as the Epilepsy and Complex Needs Lead within

the Children's Community team. Epilepsy Scotland is supporting the costs of the nurse's epilepsy specialist training.

- After seventeen years of operation, the Muir Maxwell Trust has closed. Ann and Jonny Maxwell's determination and commitment to increasing epilepsy research and knowledge has undoubtedly improved epilepsy care in Scotland. Their legacy will live on through the Muir Maxwell Centre. Alasdair thanked the Muir Maxwell Trust on behalf of the CPG for everything they have done.
2. AGM Business and the election of Office Bearers was undertaken. Alasdair Allan MSP was elected Convener, David Torrance MSP and Richard Lyle MSP were elected Deputy Co-Convenors. Members also agreed for Epilepsy Scotland to carry on providing the Secretariat on behalf of Epilepsy Consortium Scotland. Alasdair Allan MSP read the annual financial statement for the CPG and the minutes of the last epilepsy CPG were approved.
  3. Alasdair Allan MSP welcomed Gillian Smith, researcher at the University of Glasgow's Scottish Learning Disabilities Observatory. She presented recent findings from a large population study examining mortality amongst children and young people across Scotland with learning disabilities.

**Gillian Smith:** The Scottish Learning Disability Observatory is a Scottish Government funded research centre at the University of Glasgow, main function is to provide large scale population data on the health and wellbeing of people with learning disabilities in Scotland.

People with learning disabilities have a lower life expectancy than the general population and are overrepresented in deaths which are considered avoidable. Aim of the research was to look at mortality in children and young people with learning disabilities over six years to determine causes of deaths, including avoidable ones.

Data was sourced from Scotland's annual pupil census, which covers 95% of the population. Identified anyone who had additional support whilst at school, linked to National Records of Scotland deaths register allowing them to look at causes of death. 18,000 pupils were identified (2% of all school children) who had additional support needs due to learning disabilities. 800,000 pupils without learning disabilities were identified as a control group. There were more males in the learning disability group, and they were more likely to be living in areas of deprivation.

564 deaths were identified up until 2015, 0.6% of all pupils with learning disabilities. 157, deaths per 100,000 for children with learning disabilities compared to 12 deaths per 100,000 for the control group. On average, children with learning disabilities died two years younger.

Following analysis and standardisation, death was 12 times higher in children and young people with learning disabilities compared to the general population. The ratio was consistently higher for girls.

The most common underlying cause of death was diseases of the nervous system (cerebral palsy, epilepsy, neurodegenerative conditions). The next most common was lifelong conditions which was a wide-ranging group, included congenital heart problems as well as chromosomal abnormalities e.g. down syndrome. The next most common was respiratory disease, this was much lower in the control group. Cerebral palsy, epilepsy and pneumonia often combined in a cluster group of deaths. Identified avoidable deaths by using the Office for National Statistics' list of avoidable deaths. Pupils with learning disabilities often died from accidents including choking.

Pupils with learning disabilities are hospitalised at a much higher rate than the general pupil population. There is a higher prevalence of epilepsy in people with learning disabilities, and it is often more complex.

Analysed the Scottish Morbidity Register in the same population. 28% of pupils with learning disabilities were admitted to hospital, compared to 20% of pupils without learning disability. There was a statistically significant higher risk of pupils with learning disabilities being admitted to hospital over other pupils.

Emergency admission was higher amongst those with learning disabilities, particularly more for girls. This was in contrast to the control group where boys were more likely to have an emergency admission. There was a tenfold increased risk of emergency admission for children with nervous system diseases. Respiratory problems and epilepsy were the most common reasons for admission.

SLDO are using the mortality statistics with policy makers to identify and reduce amenable mortality and general mortality over the long term. They are at the preliminary stage at the moment, planning to host round tables with experts and people with learning disabilities to establish a long-term plan of action.

4. The Secretariat, Anissa Tonberg, thanked Gillian for her presentation and opened the meeting for a question and answer session.

**Anissa Tonberg** asked whether poverty is a determinant or driver for the higher mortality in pupils with learning disability.

**Gillian Smith** said the mortality figure presented is not adjusted for deprivation as the figures got too small to do further analysis. Is hopeful they can break this down further by using more data. Said poverty undoubtedly impacts access to good quality health care which is vital for this group who often have complex needs.

**Anissa Tonberg** asked what ways epilepsy can be categorised as a contributing factor of a respiratory death if it is not seizure related.

**Gillian Smith** said this is something they want to investigate further and have a plan to research whether a person with epilepsy's death is related to their epilepsy. Said it is hard to determine whether deaths are seizure related but if it is listed on their death certificate it has a role.

**Richard Chin** thanked Gillian for her presentation. Said there are problems in the death certification process as it does not capture the longitudinal issues culminating to death. There might be an association, but it is not the ultimate cause of death. The Royal College investigated this and found that a lot of the epilepsy deaths were not amenable, and their care was not suboptimal. Emphasised that despite excellent care available deaths do and will occur.

**Gillian Smith** agreed and said children will have life limiting conditions.

**Lorraine MacKenzie** asked if any research had been conducted on adults in the age group 30-40.

**Gillian Smith** said her colleague Anna Cooper has published a study on a large cohort of adults with learning disabilities in Glasgow. The study highlighted premature mortality and two-fold increase rate of avoidable death in adults with learning disabilities, many were respiratory related.

**Jane Stuart** thanked Gillian for her presentation, asked how they identified children with learning disabilities in childhood as many of her patients are not diagnosed until adulthood. Wondered if the reluctance to diagnose by educational psychologists has skewed the data towards more severe learning disabilities.

**Gillian Smith** said this is a good point. Said they looked at whether children had two records of additional support in school for learning disability. It is mandatory that if children are receiving additional support the reason must be documented.

**Jane Stuart** said there are a huge number of people with additional support needs who have been living without support.

**Gillian Smith** said having a learning disability is not a medical condition it is a very wide-ranging term. Most children in the study who have died have had a profound learning disability due to the other conditions they had. Said there is a good chance the data does not capture those with mild learning disabilities. Said we need to have a way of diagnosing children with learning disability.

**Jay Shetty** thanked Gillian for her presentation. Said it is important to think of epilepsy as a symptom rather than a diagnosis as it is a really wide spectrum. Said paediatricians across Scotland are doing a piece of work on this now and hope to report on the findings soon.

**Gillian Smith** asked if this is something which came out of their epilepsy register.

**Jay Shetty** said this study is more of a nationwide approach whilst the register is Lothian based.

**Gillian Smith** said this will be really helpful for the evidence base.

**Richard Chin** said adults with epilepsy were six times more likely to die than adults without epilepsy, those in the 16-30 bracket were at the highest risk.

**Colleen Wilson** asked how the study quantified what deaths were preventable.

**Gillian Smith** said 20% of deaths were considered avoidable using the general population list. Deaths in those with learning disabilities was three and a half times higher than those without.

**Rona Johnson** thanked Gillian for her presentation. Noted that people with learning disabilities are more likely to mouth breathe and are therefore at greater risk of respiratory infections. Asked if this might explain the higher respiratory related deaths.

**Gillian Smith** said PAMIS have been really good at looking at postural care and how that affect's a person's health.

**Catriona Jamieson** said PAMIS have been looking at avoiding organ impingement because of posture. Said this has been identified as a cause of avoidable deaths.

**Anissa Tonberg** asked what the key barriers are to policy change for people with learning disabilities.

**Gillian Smith** said there needs to be more research so we can understand what is happening over peoples' life. Said there needs to be more understanding about the barriers people with learning disabilities face e.g. communication.

The Secretariat stated that:

- the Cross-Party Group will seek to support the policy work of this research
- many members of the Cross-Party Group would be keen to join the roundtables as a result of this research

- The next meeting is due to be in December, exact date and topic will be available shortly

She thanked all for their attendance and closed the meeting.