

Epilepsy Consortium Scotland (ECS) Secretariat

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Note of Meeting – Cross- Party Group on Epilepsy, 26th January 2017

In Attendance:

George Adam MSP	Andrena Hughes, Observer
Dr James Anderson, Quarriers	Chris Jeans, SUDEP Action Scotland
Guy Armstrong, UCB Pharma	Lorraine Mackenzie, Observer
Jeremy Balfour MSP	Dr Ailsa McLelland, NHS Lothian
Jean Barclay, Observer	Carsten Mandt, NHS National Services Scotland
John Bruce, Epilepsy Connections	Pam Martis, NHS Lothian
Dr Andreas Brunklaus, NHS GG&C	Shirley Maxwell, Epilepsy Connections
Karen Burke, Pharmacist	Hilary Mounfield, Scottish Epilepsy Centre
Janette Buttle, NHS GG&C Dietician	Joe Neeson, Epilepsy Connections
Donald Cameron MSP	Allana Parker, Epilepsy Consortium Scotland
Jane Cassidy, Observer	Gil Paterson MSP
Gerry Cassidy, Observer	Sara Plummer, Blue Sky Autism project
Yasmin Erginsoy, PA to Kenneth Gibson MSP	Marjery Reid, Pharmacist
Cheryl Fisher, NHS Lothian Dietician	Carla Rennie, NHS GG&C Dietician
Dr Ruth Glynne-Owen, Blue Sky Autism project	Emily Robinson, NHS Lothian Dietician
Helen Grossi, Ketogenic Diet Coordinator	Phil Robinson, Lanarkshire Epilepsy Support Group
John Heaney, West Dunbartonshire Support Group	Brian Rocks, West Dunbartonshire Epilepsy Support Group
David Hutchinson, Special Products	John Thomson, Eisai
Kate Trenam, UCB	Anissa Tonberg, Epilepsy Scotland
Sam Whitmore, Epilepsy Connections	Lesslie Young, Epilepsy Scotland
Vita Zaporozcenko. PA to Alex Cole-Hamilton MSP	

Apologies:

Jo Campbell, ESN NHS Grampian	Yvonne Leavy, ESN NHS Lothian
Alex Cole- Hamilton MSP	Lewis Macdonald MSP
Elaine Collard, ESN NHS Highland	Ian Martin, MCN Manager
Mary Fee MSP	Peter Martin, Observer
Neil Findlay MSP	Ann Maxwell, Muir Maxwell Trust
Gerard Gahagan, Scottish Epilepsy Centre	Derek Robertson, ELN, NHS Lothian
Kenneth Gibson MSP	Dr Aline Russell, Consultant Clinical Neurophysiologist, Glasgow
Ann Greenall, ESN NHS Fife	Dr Eleonora Saturno, Consultant Neurologist, Fife
Fiona Hughes, ESN NHS Fife	Keith Small, ABPI Scotland
Jennifer Irvine, ESN NHS Lanarkshire	Dr Jane Stuart, NHS Lothian
Sylvia Lawrie, Observer	Sharon Thinn, Lead Physiologist/Service Manager NHS Fife
Margaret Wilson, ESN NHS GG&C	Susan Yule, ESN NHS GGC

1. Deputy Convener David Torrance MSP welcomed MSPs and attendees to the meeting
2. The draft note of the September 2016 meeting has been circulated. There were no amendments and it was approved. An update was given by the Convener on activities since October:
 - Richard Lyle MSP has joined this Group.
 - There have been two Members Motions regarding epilepsy from Neil Findlay MSP and Alexander Stewart MSP.
 - Convenor, Kenneth Gibson MSP has sent a letter from the Cross-Party Group to the Cabinet Secretary for Health and Sport about EEG and VT service provision, which has been passed to the Minister for Public Health & Sport Aileen Campbell MSP, who has agreed to be a guest speaker at the next meeting on the 27th April.
 - Epilepsy Scotland recently met the Minister and learned that the Scottish government is aware of the situation regarding neurophysiology services and in particular the

provision of EEG and VT. It seems this matter has been referred to the regional directors of planning, who have agreed to take this on and will be coming forward with proposals to address the issues identified.

- Convenor, Kenneth Gibson MSP has agreed to sponsor an epilepsy exhibition in the Scottish Parliament on National Epilepsy Week which is the 16th – 18th 2017.
- The Deputy Convenor invited any questions. Lorraine Kennedy raised the issue of protective headwear for people with complex epilepsy and asked for an update on the situation since the last CPG meeting. Anissa Tonberg, Policy Officer at Epilepsy Scotland, replied that she had contacted the Scottish heads of Orthotics services to discuss the issue and the hesitancy is that there are no standardised CE marked devices tested specifically for epilepsy, which leaves the prescriber open to litigation. However in looking further she has sourced two companies who seem to make CE marked helmets for epilepsy. The NHS Scottish health Technologies Group may have to examine the evidence on the issue before the NHS would agree to supply these. Lorraine Mackenzie commented that she felt it a backward step that the NHS has removed this protection for children and adults.

3. The Deputy Convenor then welcomed guest speakers Cheryl Fisher, Emily Robinson and Janette Buttle, three Daisy-Garland supported dieticians who work to implement the ketogenic diet with patients in NHS Lothian and NHS greater Glasgow and Clyde.

- **Emily Robinson** explained that in the south east of Scotland, epilepsy patients are referred to the service for a variety of concerns. Children with increased seizure activity may have increased requirements and may require high protein diets, with oral and nutritional support supplements added to meet their micro-nutrient requirements. Some children will not eat when or after they seizure and this can in turn induce more seizures and becomes a cycle of poor nutrition. In this situation, or for other situations like poor swallow, enteral feeding may be considered.
- The service also supports families to use the ketogenic diet, which is used to treat intractable epilepsy when two or more anti-epileptic drugs have failed or produced unacceptable side effects. It is a high fat, adequate protein and low carbohydrate diet which induces ketosis, however the exact mode of action is still unknown. The benefit of the ketogenic diet is that it improves the lives of patients. It can decrease the number and severity of the patient's seizures. It can reduce or remove the need for seizure medication. Patients may be more alert during the day, allowing them to develop their learning and integrate more into education and to get a better quality of life.
- The ketogenic dieticians are further supported by other health professionals who work together as a multidisciplinary team in supporting patients on the diet. For example, a consultant neurologist supports patients with complex epilepsy conditions; the ketogenic pharmacist helps to review each patient's medications so that it can be changed to a low or no carbohydrate option; epilepsy specialist nurses support the patient and provide training on blood glucose and blood or urinary ketone level monitoring. As the service in the Southeast of Scotland develops, patient numbers will significantly increase and the service will need to review whether capacity (e.g. epilepsy nurses, pharmacists, clinical support workers) is meeting demand.
- **Cheryl Fisher** explained further about the practical aspects of the diet. All children must be under the care of a paediatric neurologist prior to referral for the diet and are referred by their lead consultant. The service requires at least a minimum three-month trial of the diet. The dieticians meet with the family before commencing the diet to discuss what is involved, including daily monitoring and any risks, and look to address any issues that would influence the diet's success prior to initiation such as feeding problems, reflux and constipation. The team also discusses realistic expectations for the diet, since there is evidence that a third of patients may be seizure

free on the ketogenic diet, another third may have a reduction in their seizures and types of seizures but the remaining third may have no change at all.

- The service uses four different types of diets, which are tailored to the patient and the needs of the family. The Classical diet is very prescriptive where every child's calories, fat, carbohydrate and protein for every meal and snack is detailed out for the parents and everything must be weighed out for each meal. Following the diet requires a lot of time and organisation. The Medium-Chain Triglyceride diet, introduced in the 1970's, is a little more flexible which provides meals and options for meals but also give 'exchanges'. Dieticians tell parents how many fat exchanges they need, how many protein and carbohydrate exchanges they need, allowing them to choose what to give their child. The Modified Ketogenic, a more recent diet, is more flexible again and does not have as many strict limits on the calories and proteins. All of the diets are low carbohydrate – generally between 10-30g of carbohydrates which is a small amount, for example a little variety pack box of Rice Krispies with milk is over 20g of carbs alone, so dieticians have to be inventive. The Glycaemic Index diet is the least restrictive and can allow for between 40-60g of carbohydrates.
- Cheryl then described the training of ketogenic dieticians. This includes a four year undergraduate course in dietetics, a British Dietetics Association specialised module and British Paediatric Neurology Association courses. However the most important is probably that of training with other experienced colleagues and using the expertise from other ketogenic practitioners UK-wide and from individuals such as Regional Scottish coordinator, Helen Grossi.
- Scotland currently has 3.5 ketogenic dieticians. Since August 2016 the south east Scotland service has had a full-time post, with Daisy Garland charity funding, which covers Lothian, Borders and Fife. There is one NHS-funded whole-time equivalent (WTE) post for the North East of Scotland and a 1.5 WTE for NHS Greater Glasgow and Clyde which is funded by Daisy Garland. After 2.5 years, the Daisy Garland funding in Glasgow is set to end and the service is currently preparing a business case for the NHS to take over funding it.
- National epilepsy guidelines recommend a referral to a tertiary paediatric specialist service for consideration for ketogenic diet where drug therapy has failed. The number of referrals to the south east Scotland service has risen since 2013 and is increasing following the position being vacant for a year. 9 patients have started on diets since the service was re-established in August 2016, however there is a current waiting list of 14 patients and wait times are a concern.
- The service is currently involved in several trial studies, one is a multi-centred international trial to evaluate dietary intervention before surgery treatment for epilepsy, and a second is looking at the use of the ketogenic diet in infants below two years of age.
- **Janette Buttle** explained that the charity funding of the Glasgow service is at an end and they are currently preparing a business case asking NHS Greater Glasgow and Clyde to fund the service. Currently they have 33 children on diets and a transition service for young teenagers to move to a service for adults. The service receives between 20–25 referrals for children and if the funding is not agreed then that would significantly reduce the number of children who can access ketogenic diets. In the past, there were around 20 children on the waiting list with many waiting over a year; now all children are seen within 12 weeks of referral. There are currently 13 adults on the diet.
- In analysing outcomes for children supported by the service in the past three years, more than half of patients have had a greater than 50% reduction in their seizures, with some of these achieving a greater than 90% reduction. Some have become seizure free. Given that children may be having between 100-200 seizures a day, a reduction of that magnitude creates a massive

impact for them, their family and their quality of life. For example the service has children who, after starting the diet, can attend school full time because they are not having seizures overnight.

- Janette concluded with a plea for support to continue the service, as without ongoing funding it will return to a situation with long waiting lists and difficulty for families in accessing the diets. She highlighted the positive outcomes with children and the fact that it is the only centre in Scotland which accepts referrals for adult patients.

4. The Deputy Convenor thanked Emily, Cheryl and Janette for their presentations and invited questions.

- Anissa Tonberg asked whether, in practice, referral to the ketogenic diet service is routinely considered for children who have failed two or more anti epilepsy drugs. Janette Buttle said that this was increasingly happening, however the difficulty with older children (e.g. those over the age of 2) is that parents are often apprehensive about trying the diet because they see food as the only thing that their child has for quality of life.
- Dr Andreas Brunklaus said he felt it would be extremely detrimental if funding for the post in NHS Greater Glasgow and Clyde was not continued. He further commented that the South East Scotland service is trying to establish an adult ketogenic diet dietician, to support the transition of the increasing number of teenagers on the diet, into adult services, and would like to look at partnership working with other agencies to achieve this.
- Phil Robinson asked if there was any estimate of how many epilepsy patients across the country could potentially benefit from the diet? Dr Andreas Brunklaus said that there are at least 4,500 children with epilepsy in Scotland, of whom about two thirds will respond to conventional drug treatment. However at least 30% will not and the ketogenic diet may be useful for those children and potentially for a similar proportion of adults, also. Some children with difficult to treat epilepsy have remarkable results with the diet – from hundreds of seizures daily, to complete reduction in seizure frequency, which can transform families' lives.
- Jane Cassidy, asked why the diet has had poorer results in adults than children. Janette Buttle felt it was because children have better adherence to the diet, it is important for patients to have a good support network when on it and adults tend to struggle more with the restrictiveness of the diet.
- Dr James Anderson asked if there is any evidence that people can start the diet for them or their children by themselves? Cheryl Fisher replied that ideally people shouldn't however some people start while they are on waiting lists, which is how the modified ketogenic diet came about because people had varied the diet before they went to the clinic and it highlighted that the diet did not necessarily have to be as restrictive as the Classical diet. However, the diet has side effects and risks and patients require regular monitoring including nutritional blood tests to check for deficiencies.
- Vita Zaporozcenko asked if there was any reluctance on the part of the specialists to refer patients to the service? Emily Robinson and Janette Buttle reported that paediatric neurologists around Scotland were very positive about referring children to the service, and that adult referrals could potentially be much higher but that this may come as evidence grows and services develop.
- Helen Grossi outlined the North of Scotland ketogenic diet service, which covers from Shetland down to Dundee with just two part-time dieticians.

- Dr Ailsa McLellan mentioned that the Scottish Paediatric Epilepsy Network runs educational roadshows around Scotland including the ketogenic diet, and has a continuing epileptic seizures pathway which specifically mentions the diet. With at least 1,500 children with poorly controlled epilepsy, she expects that waiting lists will increase significantly. Janette Buttle commented that around 25–30 patients is an appropriate caseload for a full time dietician.
- Gil Paterson MSP asked if there would be a negative impact to the health service and its costs if this service wasn't available? Cheryl and Janette replied that if you have a child with very difficult to control epilepsy, controlling the seizures with diet can eliminate costs associated with bed space in hospitals, ongoing multiple A&E admissions, and additional medicines.
- Chris Jeans asked if the impact of the diet remains as the children grow in to adolescence and in to adulthood? Janette Buttle replied that children usually attempt to wean off the diet after two years. They have had several patients who have started it as children and had very good results, but when reaching 16/17 years old have had seizures and asked to go back on the diet. Research is beginning to indicate that it may work better as a longer-term treatment for adults. Since it is a high-fat diet, adults on it are carefully monitored for cardiac issues as the long-term side effects of the diet are still unknown.
- Jean Barclay asked if we know why it works? Helen Grossi replied that despite research being conducted worldwide, there is still no conclusion on why it is a successful treatment.

5. The deputy Convenor invited any wider issues to be raised.

- Anissa Tonberg raised the issue of sharp price increases in two epilepsy drugs used for infantile spasms and difficult to manage epilepsy. Synacthen Depot has increased from £4.00 to £346.00 for a 1ml ampoule, and Nitrazepam has increased from £7.00 to £164.00 for 100mls. Some specialist nurses report struggling to get these drugs prescribed for children because of the cost. She appealed to the group for any more information about the extent of the problem. Pharmacist Margery Reid reported that a number of drugs have undergone enormous price increases and that hospitals are unable to keep a stock of such expensive medicines, which can delay treatment for some patients as special permission must be sought to dispense the treatment and the drugs themselves must then be sourced.
- George Adam MSP suggested asking drug companies to attend and explain to the group what is happening and why drugs are costing so much. He reported having useful experiences with the MS CPG in engaging pharma companies to talk about the balances between NHS funding and patient access.

6. The Deputy Convenor thanked everyone for attending and details of future meetings will be circulated in due course (27 April 2017).