NeSCANN Annual Report
2012-13
North Scotland Child and Adolescent Neurology Network
# NeSCANN
North Scotland Child and Adolescent Neurology Network

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1. **Introduction**

The North Scotland Child and Adolescent Neurology Network (NeSCANN) comprises multi-disciplinary teams in each of the 3 main centres of Aberdeen, Dundee and Inverness, supports children with epilepsy, neurological and neurodisability conditions across 5 Health Board areas in the North of Scotland. 2013 sees the 10th anniversary of the network which commenced in a clinically driven informal way in 2003 with the support and co-operation between Grampian and Tayside Health Boards. Since then the network has been formalised and has continued to progress and develop well year on year through the dedication of its multi-disciplinary staff in providing the best possible care for their patients as close to their homes as possible.

The National Delivery Plan investment from 2008-2011 was the first major investment in NeSCANN since its inception. NDP provided funding of sessions in medical staffing, therapies, neuropsychology and specialist nursing. While many of the new posts are hosted within an individual Health Board, many work across the region to support the work of NeSCANN. This has ensured equitable access to the best secondary and tertiary multi-disciplinary services across the North.

The main **aims and purpose** of the network are to –

- provide clinical care of the highest quality
- provide safe and appropriate care as close to the patient’s home as possible
- ensure the appropriate skill mix of professionals
- encourage staff training and education
- maintain and develop professional expertise locally and across the network.
2. **Background**

2.1 **Benefits of Networking**

There can be many positive benefits from working in a network. Some good examples of positive networking in NeSCANN are as follows:

- Provision of locally delivered clinics in the 3 main centres but also including Perth, Elgin, Orkney and Shetland, have meant that patients have access to the best possible services delivered as close to their homes as possible.
- Increased staffing and multi-disciplinary teams link together to share good practice and provide a co-ordinated approach across the North.
- Sharing of expertise has meant that staff have access to high quality peer support. Staff have felt empowered due to sharing of information and increased opportunities for training and education, e.g. Brainwave (Ninewells), NOD (RACH), lunchtime case discussions (Inverness).
- Faster access to Epilepsy Specialist Nursing, AHPs and Psychology has meant improved support for patients and families and their ability to cope with their child’s disease. These have also improved clinical outcomes.
- Transition clinics – there are good links with adult colleagues and nurse-led clinics are provided in addition to Consultant-led clinics.
- Video-conference/telehealth technology has enabled review consultations by VC reducing the need for patients and families to travel to a main centre.
- Work has taken place collaboratively with regards standardisation of care pathways/guidelines/information to patients and families across the network.
- There is added value of working with similar regional networks in gastroenterology and respiratory which map to the same catchment area.
- A regional model of care for any service is more likely to be funded by regional or national bodies than a proposal from professionals working separately in different centres.

2.2 **Network Links**

**North of Scotland Planning Group – Child Health Groups**

Dr Martin Kirkpatrick (Clinical Lead) and Carolyn Duncan (Network Manager) are members of the North of Scotland Child Health Clinical Planning Group (CHCPG) and Child Health Operational Delivery Group. The CHCPG takes place 4 times per year. The CHCPG drives forward the strategic aims of child health networks in the North in line with national drivers and initiatives. The Child Health Operational Delivery Group (formerly the Clinical Leads’ Group) is a forum to discuss more operational than strategic issues across the region and to date includes Service Managers from Grampian, Highland and Tayside.

**National Paediatric Epilepsy Surgery Service**

Network staff are involved in and support this national service for patients with epilepsy. Multi-Disciplinary Team meetings, with video-conference facilities, take place monthly and are held on a rotating basis between Dundee, Edinburgh and Glasgow, to discuss patients who may go forward for epilepsy surgery either in Edinburgh or at Great Ormond Street in London. Martin Kirkpatrick is the North of Scotland lead for this service.
Scottish Paediatric Epilepsy Network (SPEN)

There are continued strong network links with the Scottish Managed Clinical Network for Epilepsy, with Dr Ann O’Hara, from Royal Aberdeen Children’s Hospital as Lead Clinician of the network. Members of NeSCANN attended the SPEN Members’ Day in Stirling in November where topics such as network updates, Epilepsy 12, the Clinical Audit System and planning were discussed.

Scottish Muscle Network

There continues to be links with the Scottish Muscle Network with clinicians being closely involved in developments and service improvement updates. Although not part of this network, the Scottish Government has provided funding for 2 years for 3 Neuromuscular Care Advisor posts (1 in each of North, South & East and West) for all patients with neuromuscular disorders, following the termination of funding for posts at DMD. Mrs Emma Condon took up post in the North in January 2013 and will be linking closely with paediatric and adult colleagues across the region. She will be looking to scope, agree and establish current and future pathways, standards, guidelines and audits and look at the education needs of the workforce.
3. Updates

3.1 NeSCANN Steering Group

Three steering group meetings by video-conference took place during the year in March, June and September, with no major changes to the membership of the group. It has been decided to increase these in number to 4 during 2013. In addition, subgroup meetings on training and education and web developments have also taken place during the year. Dr Martin Kirkpatrick chairs the meetings as Clinical Lead, supported by Carolyn Duncan, Network Manager. There have been a wide variety of topics discussed during the year, such as staffing, the work plan, training and education, service developments, care pathways, standards and guidelines, research and audit, IT systems and web developments.

3.2 Staffing

A list of staff involved in the network during the year is attached at Appendix 1.

The National Delivery Plan (NDP) provided significant funding for posts which are now well embedded into services with no major staffing changes during the year. NDP provided funding for a physiological technician post shared across medical specialties, however the funding for the neurology part of the post which will be used to develop a paediatric telemetry service in collaboration with the adult neurophysiology team in due course. Positive discussions are ongoing between Dr Ayaz Shah, NHS Grampian child health management and ARI management teams regarding the development of an ambulatory video-telemetry service in Grampian.

3.3 Network Developments

A large number of joint specialist tertiary, secondary care and nurse-led clinics are delivered in each of the 3 main centres in Aberdeen, Dundee and Inverness, covering neurology, epilepsy and 1st seizures, epilepsy transition, neuro-ketogenic diet and combined clinics with surgical and medical specialties. Specialist clinics are also delivered in Perth, Elgin, Orkney and Shetland.

3.3.1 Highland/Moray Epilepsy Clinics

Following NHS Highland and NHS Grampian planning meetings at the start of 2012 agreement was reached to commence bi-monthly epilepsy clinics in Dr Gray’s Elgin. These commenced from January 2012 delivered by Dr Alan Webb and supported by Epilepsy Specialist Nurses from Highland and Grampian. EEGs for Moray patients are mostly being carried out in Inverness as this service is almost immediately available at Raigmore. There are twice monthly epilepsy clinics with nurse support and access to EEG on the same day at Raigmore which has proved to be extremely valuable. There are also epilepsy clinics in both Fort William and Caithness on a quarterly basis.

A large amount of work has been carried out looking at current service provision in both health boards and in defining the epilepsy service resources moving forward. Discussion on appropriate transition arrangements for patients continues to be extremely important.

Dr Webb will liaise with NHS Grampian Consultant Paediatricians and network tertiary specialists, regarding future epilepsy service provision in Moray.
3.3.2 Islands’ Clinics

Specialist clinics continue to be delivered by Dr Kirkpatrick in Shetland (2 per year) and Dr Jollands in Orkney (2 per year) which are supported by Epilepsy Specialist Nurses to enhance locally delivered patient care. This service includes additional follow-up review consultations by video-conference with Orkney and Shetland patients which are also supported by Specialist Nurses. NDP helped to fund these sessions and with the use of telehealth facilities ensures the delivery of care close to patients’ homes as well as reducing disruption to families and having to travel long distances to be seen.

Network colleagues were delighted when the Orkney Child Health Service Manager formally agreed that Penny Martin, Physiotherapist, could continue to provide valuable co-ordination, support and liaison to professionals and families as lead contact clinician for paediatric patients and clinics on a permanent basis.

3.3.3 Intrathecal Baclofen Clinics

Patients who have Baclofen pumps fitted are treated during routine neurology clinics in the main centres at present however numbers have increased and it is the network’s aspiration to set up additional dedicated ITB clinics in Aberdeen and Inverness in future. Discussions have already commenced and it is hoped that these additional improvements to services can be established during the coming year.

3.4 Work Plan

Work on items in the 2011-13 work plan progressed well during the year (Appendix 2) -

- Map develop and agree care pathways for epilepsy
- Develop information resources for patients
- Continue to develop education framework
- Implement cross-boundary data collection IT system
- Develop a universal standard of training & education delivered by Epilepsy Specialist Nurses
- Audits of clinical care

The work plan is continually performance managed with a red/amber/green traffic light system. Some of the existing items in relation to the development of guidelines and care pathways, clinical data collection and audit will be extended and new items added to update the plan for 2013-15.

Data management and a fit for purpose IT system that can be accessed from anywhere in the North is still high on the agenda for NeSCANN as well as other child health networks in the region. Progress with adoption of the NSD Clinical Audit System has been slower than expected during the year. Discussions will continue with the Scottish Paediatric Epilepsy Network in order to achieve a system that will provide staff with the ability to collect epilepsy as well as neurology data for North patients and for staff to have the capability to carry out further audits. Discussions continue regarding the inclusion of neurology fields in a North version of the system.

Work has taken place during the year on care pathways and guidelines. There has been Scotland-wide agreement on national guidelines for Selective Dorsal Rhizotomy which had been worked on by the Scottish paediatric orthopaedic surgeons working with a range of neurology and neurodisability clinicians. The network also worked on agreeing a continuing epileptic seizures care pathway and work will continue with regards pathways for Moray epilepsy patients.
3.5 Training & Education

The network is committed to ensuring staff are well trained and highly skilled. Monthly multi-disciplinary meetings take place in the 3 main centres i.e. Brainwave (Ninewells), Neurology Open Day (RACH) and Raigmore, Inverness, lunchtime sessions alongside the visiting Consultant Neurologist clinics, which provide regular teaching and educational forums for learning, e.g. discussions on complex cases, developments, brain imaging and neurophysiological investigations. Topics covered during the year included:

- Feedback from the British Paediatric Neurology Association conference
- managing chronic daily headaches
- children with complex needs review
- teenagers and transition
- update on Spina Bifida
- acute Brain injury advances and rehabilitation

In addition, a regular bulletin of local, regional and national neurology educational opportunities accessible to all staff is published and circulated across the North of Scotland.

3.5.1 Paediatric Neuro-oncology Study Day

A successful network study day organised by Dr Jollands took place on 1st October 2012 at Ninewells which was well attended. Topics during the day included common clinical presentations of CNS (Central Nervous System) tumours in childhood, radiological and pathological features, the role of surgery, radiotherapy and chemotherapy in the management of CNS tumours and the neuropsychological perspective on cognitive outcome post tumour treatment. Mr Mark Brougham, Royal Edinburgh Children’s Hospital also presented on ‘HeadSmart’, a project and web site promoting early diagnosis of brain tumours in childhood.

3.5.2 PET (Paediatric Epilepsy Training) courses

Paediatric Epilepsy Training (PET) courses began to be developed by the British Paediatric Neurology Association (BPNA) in 2004. They aim to support training for any health professional involved in the care of children and young people with an epilepsy or seizure disorder. PET1, PET2 and PET3 are each designed for different multi-disciplinary groups of health professionals.

Several members of NeSCANN were involved in teaching at the 2012 Scottish PET1 course in Dundee on 15th June 2012. Forty people attended there was very positive feedback. A total of 30 clinicians from across the North attended either a PET 1, 2 or 3 course during the year. It is hoped another PET1 course can be organised for Scotland in 2013. Revisions of the PET2 and PET3 courses are also underway, with the possibility of an additional level of PET course in between PET2 and PET3 now being discussed.

3.5.3 Nurse Education & Training sub-group

The Epilepsy Specialist Nurse Training & Education Group completed its excellent work during the year on standardising disease and treatment information provided to patients and families across the network. Information packs were reviewed and the generic standards for the delivery of training provided to patients, families, carers, medical, social care and education staff was also agreed.
General principles were agreed regarding the type of written information provided based on the recommendations of the Scottish Intercollegiate Guidelines Network, SIGN 81 guideline ‘Diagnosis and management of epilepsies in children and young people’.

A comprehensive folder was produced to be able to be accessed by all health professionals in Aberdeen, Dundee and Inverness, encompassing the following topics:

- Teaching offered by Epilepsy Specialist Nurses
- JEC Syndrome Diagnosis Sheets
- Medicines for Children AED Fact Sheets
- Information Packs Age Appropriate
- Information Leaflets – First Seizure etc
- Standard Introduction Letter
- Parental Education/Training Checklist
- Epilepsy Nurse Service Audit Questionnaire
- Education/Support Staff Training Checklist
- MCN Care plan 2012
- Guideline - midazolam
- Personal Epilepsy Profile
- Training Certificate
- JEC Guideline on Training Standards for the administration of Buccal Midazolam

Further work is ongoing on network SUDEP (Sudden Unexplained Death in Epilepsy) information so that a clear policy on information discussed with families is agreed regionally following the Fatal Accident Inquiry report in 2011 on 2 deaths in Scotland and a subsequent formal response from SPEN.

### 3.5.4 Network Website

The NeSCANN web page is currently included in the North of Scotland Planning Group website. Network discussions have taken place with regard to the possibility of setting up a network specific website in future so that it is easier to identify and easier for families and professionals to access. A group met during the year to decide on the neurology and epilepsy information that should be included for patients and families as well as regional guidelines and network documents for professionals. It was agreed that it will be important not to duplicate the posting of documents, policies or guidelines that are already posted and updated by external organisations.

### 3.6 Epilepsy Specialist Nursing (ESN)

Demands on the Epilepsy Specialist Nurse resource continues to rise in the 3 main centres. Numerous contacts with families are made or received on the phone or by email on a daily basis. A significant amount of monthly training was also undertaken by the nurses to a wide variety of professionals during the year, e.g. patients, families, carers, medical, social care and education staff. ESNs continue to provide dedicated, timely support and care for patients and their families as close to home as possible.

**Aberdeen**

Jo Campbell and Ena Cromar are now both qualified non-medical prescribers and can carry out ECGs and venepuncture for patients, improving the service to patients by reducing the number of times needed to travel to attend appointments. The age range in Grampian increased from 14 to 16 years of age from autumn 2012 and the total number of new children referred to the ESN service last year was 65.

A large number of excellent epilepsy training sessions for families and professionals were rolled out during the year. In 2012, 285 people were trained at the whole day session.
Epilepsy Awareness and Emergency Medication training days. 280 people were trained with regards to specific patients, from 41 schools and 16 respite care/private nurseries across Grampian, Orkney and Shetland.

**Inverness**

Jan Rosie (Mackenzie) is currently on maternity leave and her full-time post is being covered by Kelly McBeath on a part-time basis. Kelly has been a great asset to the service and this has ensured continued additional ESN support albeit on a reduced hours basis.

ESNs have continued to support Dr Alan Webb in his Consultant with a special interest in epilepsy role. Epilepsy clinics in Raigmore twice per month are now well established in addition to the monthly tertiary specialist clinics. Discussions and planning are ongoing with regards the introduction of a 1st seizure clinic and establishing a teenage clinic.

Epilepsy clinics are also provided in Fort William and Caithness (4 per year in both) by Dr Webb and ESNs. In addition, 5 clinics were delivered in Dr Gray’s Hospital, Elgin in 2012. These clinics are full day clinics seeing up to 12 patients. ESNs also attend the Community Consultant Paediatricians’ clinics with known epilepsy patients.

Valuable training to schools, nurseries, after school clubs, students (both medical and nursing) and nursing staff continued to be provided during the year. At present the training for schools is carried out in individual schools where a child has epilepsy. This can have ESNs working from Durness to Knoydart! We are looking to start a training day primarily in Inverness, for non-health professionals that would be open to any relevant staff to attend.

**Dundee**

During the year Karen Lawrence and Pauline McEachen continued to provide visits and training to a wide variety of parents and families, health professionals and social care and education staff across Tayside. A programme for Epilepsy Awareness and Medication training is carried out monthly at Ninewells.

Work is ongoing to review the Tayside Specialist Nurse referral form following comment in the Epilepsy 12 report. The ESN service provided to teenagers is being reviewed with plans to develop a nurse-led clinic in future. Karen Lawrence will apply to study on the Nurse Prescribing course from September 2013. In collaboration with medical staff, development of a Tayside epilepsy service web page or app, to include general epilepsy and first-aid management information, is being investigated.

**3.6.1 Network Epilepsy Specialist Nurse Service questionnaire**

An ESN network questionnaire is in the final stages of preparation for being undertaken in Spring 2013 to look at the quality improvements that have been made to patients’ and families’ lives following the introduction of the Epilepsy Specialist Nurse posts from 2004. This follows on from previous Grampian questionnaires in 2005 and in 2010 where valuable insight and very good feedback was received on the benefits and importance of the dedicated, easily accessible support the ESN has provided, as well as improved outcomes for patients and families.

Ena Cromar has collaborated with the Clinical Effectiveness Department in NHS Grampian in producing the questionnaire for the network. The questionnaires will be completed anonymously and it is the intention that they will be handed out by outpatient clinic staff that are not part of the network, requesting the patient/families to
return it to an appropriate collection point at the end of the clinic. Completed questionnaires will be returned to the Clinical Effectiveness Team for analysis at a later date.

It is hoped that the effectiveness of the ESN Service will highlight the excellent work that is being carried out currently and in particular following the increased 0.5 wte NDP investment in Epilepsy Specialist Nursing in each of the 3 main centres.

3.7 Allied Health Professionals

3.7.1 Ketogenic Diet Co-ordinator (Helen Grossi)

This part-time post is now fully established across the North with Helen providing valuable expert advice and support to patients with complex epilepsy, who have failed on two or more anti-epileptic medications and to clinical staff. Evidence shows that the diet, which is individually calculated, very high in fat, low in carbohydrate and adequate in protein, produces an anticonvulsant effect on patients.

A total of 13 patients are currently on a ketogenic diet, with 6 patients who were on the diet as part of their treatment regime recently coming off it. Advice was also provided to 3 patients and families, who did not wish to proceed with going on the diet and 3 families who have tried the diet and been unsuccessful.

Helen has delivered training sessions in Grampian, Highland and Tayside to update dietitians and nursing staff. This has also enabled the upskilling of local Dietitians to be able to deliver ketogenic diets to patients. She also provided 6 useful training and awareness sessions to education and social care staff across the region, so that they are fully aware of the needs of this patient group.

Helen is also able to attend regular neurology network operational and steering group meetings, as well as the Scottish Ketogenic Dietitians meetings to keep abreast of regional and national work streams and plans. She has also been invited to talk about the ketogenic diet at national conferences.

Helen is also a member of the Medical Board for Matthews Friends, the UK charity which supports patients and families on the Ketogenic Diet.

Tracy Cameron, Band 6 Paediatric Dietitian, has been seconded to the Ketogenic Diet in Tayside for 2 years from May 2012 (0.4 WTE) and has been actively involved in the care of individuals currently on the Ketogenic diet in Tayside. This involves attending Ketogenic clinics, domiciliary visits and reviewing inpatients. She has familiarised herself with the eKM (electronic Ketogenic Calculator) and calculates requirements and meal plans for the classical diet. In the forthcoming year she plans to continue her contribution to the workload in Tayside, working towards a medicine database and starter recipes.
4. Research & Audit

4.1 ‘Epilepsy 12’

NeSCANN clinicians were closely involved during the year in this national audit of the care of children with newly diagnosed epilepsy. The principal part of the audit comprised 12 Performance Indicators referenced to SIGN and NICE guidance and the Patient Experience Questionnaire used nationally was designed and piloted in Dundee. The paediatric units in the north of Scotland were in the pilot phase together with Cambridge and Cardiff. The report was published in September 2012 and gave a “snapshot” of care to almost every child with a new diagnosis of epilepsy over a 6 month period for the whole of the UK in 2011. The data provided from the North was an amalgamation of the 3 mainland Health Boards and provided feedback to allow comparisons with other units in the UK. Aberdeen, Dundee and Inverness subsequently produced individual action plans based on the findings.

Units in the UK that did not perform well were asked to show what they could put in place to improve and units that performed well were asked to feedback to Epilepsy 12 to explain how they managed to achieve the performance indicators so that other units could learn from their work. The main issues highlighted were significant variation in Epilepsy Specialist Nurse provision and teenage clinic resources across the UK, although overall Scotland performed well in these areas. The return rate from the anonymous patient questionnaires was poor and some only limited conclusions could be drawn from that aspect of the audit.

On the whole, each of the 3 main centres in North Scotland came out well in Epilepsy 12. Follow-up work on items in the unit action plans continues with discussion on progress taking place at quarterly network steering group meetings.

4.2 Future Audit - Epistatus/Buccal Midazolam

Much discussion has taken place during the year with regards the prescribing and format of use of different preparations of buccal midzolam used to treat prolonged seizures in children. There has been concern nationally with regard to age-related doses and safety issues around the current prescribing of the 2 different preparations, i.e. when there have been differences between hospitals prescribing one product and community pharmacists prescribing another. SPEN provided a key response regarding buccal midazolam prescribing following a letter from the Chief Pharmaceutical Officer. In the meantime SPEN has issued a statement recommending ongoing use of a single preparation to avoid confusion. It is likely that a network audit on the use of midazolam will be looked at in the coming year.
5. Plans for Next Year

5.1 Network study day 2013

As it is the 10\textsuperscript{th} anniversary of the network in 2013, it is the intention that a joint study day will be held in the autumn with the North of Scotland Gastroenterology, Hepatology and Nutrition Network that is also celebrating its 10\textsuperscript{th} anniversary. Topics to be discussed will focus on brain and gut conditions that affect types of patients known to both networks.

5.2 Epilepsy 12 project extension

Network staff will continue to be involved in the national audit during 2013. Additional funding for 2 years from winter 2012 to extend the work on an audit tool was agreed by the Health Quality Improvement Partnership (England and Wales) and Health Improvement Scotland. Future audit work will include refining the performance indicators in terms of re-looking at the parent questionnaire resulting in a better response rate. Data entry for Round 2 of the audit opened on 1\textsuperscript{st} March 2013.
6. Key Challenges

6.1 Clinical data – Clinical Audit System

A major challenge for NeSCANN and other networks’ members is the management of patients who have to move across health board boundaries to receive treatment. Access to comprehensive clinic data continues to be an issue for all child health networks across the North of Scotland due to slower than anticipated progress with the national Clinical Audit System. There have been several discussions during the year with the system developer concerning the technical aspects for a North of Scotland version. Adoption of the system by NeSCANN has been further complicated due to interconnectivity and governance arrangements with the national Scottish Paediatric Epilepsy network version of the system.

The SPEN version of the system and data input commenced as a pilot project during the summer of 2012 in Glasgow, with time taken to input information being found to be lengthy due to the speed of the system, however this is now improving. Discussions are ongoing in the SPEN Governance group in relation to North patients to ensure the system encompasses information appropriately on all NeSCANN patients.

Work separate to the Clinical Audit System is ongoing with North Board e-Health departments to integrate SCi Stores across health board boundaries which will allow clinicians timely access to patient information prior to adoption of the Clinical Audit System. It remains the intention of the network and NoSPG to have a version of the NSD funded system to ensure easy access to information on network patients.

6.2 Access to Clinical Portals

Clinicians working across Health Board boundaries continue to have issues with accessing other Boards’ IT systems to view results and to sign clinical letters when working outwith their home Board. It has been possible to gain access whilst delivering clinics in specific Health Boards however access to individual systems from a remote location remains problematic and not ideal from the aspect of clinical governance. Sci Stores access as mentioned above does not resolve the issue of access to Grampian ECCI letters (clinical letters) but this can now be addressed by applying for remote access through the e-Health departments.
7. **Looking Ahead**

The network will continue to build on the excellent collaborative work carried out across the region over the past 10 years and looks forward to progressing network developments for the benefit of staff and patients in 2013. Our multi-disciplinary teams of conscientious, hardworking, well trained staff continue to make a big difference and to improve standards of care for patients with a neurological condition across the North of Scotland.

Some of NeSCANN’s priorities for the coming year will be to:

- increase epilepsy clinics in Elgin from quarterly to monthly
- develop Intrathecal Baclofen clinics
- further develop care pathways and guidelines for the network
- develop a specific NeSCANN web site
- collaborate with SPEN and NSD to ensure the Clinical Audit System meets the needs of the network
- work on action plans and contribute to the 2nd round of Epilepsy 12.
## Appendix 1 –

### North Scotland Child & Adolescent Neurology network staff involved in delivery of NeSCANN

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<thead>
<tr>
<th>Network Management</th>
<th>POST</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Dr Martin Kirkpatrick</td>
<td>Consultant Paediatric Neurologist</td>
<td>Clinical Lead</td>
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<tr>
<td>Carolyn Duncan</td>
<td>Child Health Network Manager</td>
<td>Also Network Manager for Gastroenterology and Respiratory NoS networks</td>
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### Aberdeen

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<thead>
<tr>
<th>NAME</th>
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<tbody>
<tr>
<td>Dr Ayaz Shah</td>
<td>Consultant Paediatrician</td>
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<tr>
<td>Dr Elma Stephen</td>
<td>Locum Consultant Paediatrician</td>
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<tr>
<td>Dr Ann O'Hara</td>
<td>Associate Specialist</td>
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<tr>
<td>Diane Honeyman</td>
<td>Medical Secretary</td>
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<tr>
<td>Jo Campbell</td>
<td>Specialist Epilepsy Nurse</td>
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<tr>
<td>Ena Cromar</td>
<td>Specialist Epilepsy Nurse</td>
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<tr>
<td>Dr Bruce Downey</td>
<td>Neuro-Psychologist</td>
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<tr>
<td>Hilary Rennie</td>
<td>Dietitian</td>
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<tr>
<td>Winnie Taylor</td>
<td>Lead Speech &amp; Language Therapist</td>
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<td>Jo Thomas</td>
<td>Occupational Therapist</td>
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<tr>
<td>Jane Tewnion</td>
<td>Physiotherapist Neuro-muscular adviser</td>
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<tr>
<td>Julie Ralston</td>
<td>Dietitian – Dr Gray’s Elgin</td>
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<tr>
<td>Physiological Technician</td>
<td>0.3 wte of funding will be used to set up ambulatory VTEM service</td>
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### Dundee

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<tr>
<th>NAME</th>
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<tbody>
<tr>
<td>Dr Martin Kirkpatrick</td>
<td>Consultant Paediatric Neurologist</td>
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<td>Dr Alice Jollands</td>
<td>Consultant Paediatric Neurologist</td>
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<tr>
<td>Dr Linda Clerihew</td>
<td>Consultant Paediatrician</td>
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<tr>
<td>Sheila Kerr</td>
<td>Medical Secretary</td>
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<tr>
<td>Karen Lawrence</td>
<td>Specialist Epilepsy Nurse</td>
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<tr>
<td>Pauline McEachen</td>
<td>Specialist Epilepsy Nurse</td>
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<tr>
<td>Aileen McCafferty</td>
<td>Neuro-psychologist</td>
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<tr>
<td>Anne Keddie</td>
<td>Physiotherapist – Neuro-muscular</td>
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<td>Jo Armstrong</td>
<td>Physiotherapist – Intrathecal Baclofen</td>
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<td>Helen Grossi</td>
<td>Ketogenic Dietitian</td>
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<td>Heather Mitchell</td>
<td>Dietitian</td>
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<td>Zoë Whyte</td>
<td>Occupational Therapist</td>
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<tr>
<td>Dr Alan Webb</td>
<td>Consultant Paediatrician with a Special Interest in Epilepsy</td>
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<tr>
<td>Mandy Craib</td>
<td>Medical Secretary</td>
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<tr>
<td>Dr Linda MacLellan</td>
<td>Consultant Paediatrician</td>
</tr>
<tr>
<td>Dr Lesley Henderson</td>
<td>Consultant Paediatrician</td>
</tr>
<tr>
<td>Kelly McBeath covering for Jan Rosie</td>
<td>Specialist Epilepsy Nurse</td>
</tr>
<tr>
<td>Kirsteen Mackintosh</td>
<td>Specialist Epilepsy Nurse</td>
</tr>
<tr>
<td>Nikki Strachan</td>
<td>Dietitian</td>
</tr>
<tr>
<td>Judy Shalcross</td>
<td>Dietitian - Wick</td>
</tr>
<tr>
<td>Dr Tracy McGlynn</td>
<td>Psychologist</td>
</tr>
<tr>
<td>Dr Rachel Smith</td>
<td>Psychologist</td>
</tr>
</tbody>
</table>

### Shetland

<table>
<thead>
<tr>
<th>NAME</th>
<th>POST</th>
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<tbody>
<tr>
<td>Dr Susan Bowie</td>
<td>GP with a Special Interest</td>
</tr>
<tr>
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<td>GP with a Special Interest</td>
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</tbody>
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Specialist Epilepsy Nurse Jan Rosie on Maternity leave from July 2012
<table>
<thead>
<tr>
<th>NAME</th>
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<tbody>
<tr>
<td>ORKNEY</td>
<td></td>
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<tr>
<td>Catriona McCallum</td>
<td>Dietitian</td>
</tr>
<tr>
<td>Penny Martin</td>
<td>Physiotherapist/Practitioner with Special Interest</td>
</tr>
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</table>
### Objectives

#### Formalise a Paediatric Neurology Steering Group

- Identify membership across all North of Scotland Health Boards and ensure regional priorities for the network
- Develop role and remit of group
- Agree schedule of meetings
- Agree upon annual work plan
- Develop a performance monitoring framework to monitor the work plan

**Timescales:** 2011

**Lead Professionals:** M Kirkpatrick, C Duncan

**Progress at December 2012:** Steering group established and work plan agreed.

#### Establish safe storage for clinical video & photography

- Ensure safe/secure storage facility of clinical patient videos and photography
- Liaise with local Health Board professionals to identify and address gaps in local policies
- Agree upon an implementation strategy, initially at the Child Health Clinical Planning Group level

**Timescales:** 2011-2013

**Lead Professionals:** A Jollands, A Shah, M Kirkpatrick, C Duncan

**Progress at December 2012:** NHS Grampian and NHS Highland work to existing policies. Draft Tayside policy agreed & awaiting publication. Storage issues being resolved.

#### Increase VC consultations with patients in remote locations

- Increase tertiary support to improve local access and to reduce staff/patient/family travel time and reduce costs
- Build on Ninewells telemedicine evaluation carried out in 2010 and carry out evaluation of clinical VC consultations
- Continue review of functioning of existing infrastructure and of gaps in current service

**Timescales:** 2011-2012

**Lead Professionals:** A Jollands, C Duncan

**Progress at December 2012:** Clinical VC consultations ongoing.

#### Map, develop and agree care pathways

- Develop North region care pathways to ensure consistency across the network, enhancing links to national/other regional networks
- Identify existing care pathways and any gaps
- Link with national/regional groups to inform existing or new network protocols, standards and referral pathways
- Agree upon neurology care pathways for western Grampian area

**Timescales:** 2011-12

**Lead Professionals:** A Jollands, H Grossi, J Campbell, J Armstrong

**Progress at December 2012:** Work ongoing between NHS Grampian and NHS Highland re pathways for Moray epilepsy. Work done on network continuing seizures protocol & national SDR.

#### Develop information for patients

- Enhance patient/families' knowledge of service and of disease information
- Develop patient information and involvement leaflets
- Investigate Web possibilities to develop network website

**Timescales:** 2011-13

**Lead Professionals:** A Jollands, H Grossi, J Campbell, J Armstrong

**Progress at December 2012:** NeSCANN web page now set up on NoSPG web site – future content in discussion.
<table>
<thead>
<tr>
<th>Objectives</th>
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<th>Tasks</th>
<th>Time-scales</th>
<th>Lead Professionals</th>
<th>Progress at December 2012</th>
</tr>
</thead>
</table>
| Continue to develop education framework | Scope current training provided, training needs of network staff and develop a planned curriculum of Continuing Professional Development | • Complete Training Needs survey  
• Identify service and staff needs  
• Map educational opportunities – local/ regional/national | 2011 | A Jollands  
C Duncan  
J Campbell  
E Cromar | Regular training and education opportunities bulletins distributed regionally |
| Implement cross-boundary data collection IT system | Improve clinical data collection by means of a Clinical Audit System to have ability to audit and provide high quality care to patients | • Gain agreement at NoSPG to develop and to provide funding so that NeSCANN can input to SPEN instance (which include neurology data sections) | 2011-13 | M Kirkpatrick  
A Jollands  
C Duncan | Agreement has been reached with NoSPG Child Health management that NeSCANN clinicians will adopt the SPEN instance of the Clinical Audit System when system goes live from autumn 2012 |
| Develop a universal standard of training & education delivered by Epilepsy Specialist Nurses across the region | Review and standardise epilepsy training packages and protocols for primary care and other care professionals involved in children's epilepsy | • Collate and review resources delivered by children's epilepsy nurses.  
• Develop CPD currently delivered to include working with difficult families, children with behavioural difficulties, transition, VNS, ketogenic diet support, drugs information & prescribing  
• Develop standard protocols and guidelines e.g. emergency medication, seizure first aid, training for parents/carers/Education, teenage services and transitional care | 2011-2013 | A Jollands  
J Campbell  
J Mackenzie  
K Lawrence | Group set up and huge amount of work undertaken to standardise training and information packages given to patients and families, carers and staff. Standards document was agreed Spring 2012.
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<tr>
<td>Audit clinical care</td>
<td>Measure performance indicators in children's epilepsy care and review parents’ and carers’ experiences of service provided</td>
<td>• Participation in and collation of data for the Epilepsy 12 national audit</td>
<td>Sept 2012</td>
<td>M Kirkpatrick</td>
<td>Collaborative work carried out by staff in 3 main centres to collate and submit data to the national audit team. Local action plans drawn up in Dundee, Aberdeen and Inverness.</td>
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</table>

**Red/Amber/Green status**

- red - not on target/little or no progress
- amber - satisfactory, significant progress to date but further work required
- green – the network has been successful in achieving the objective