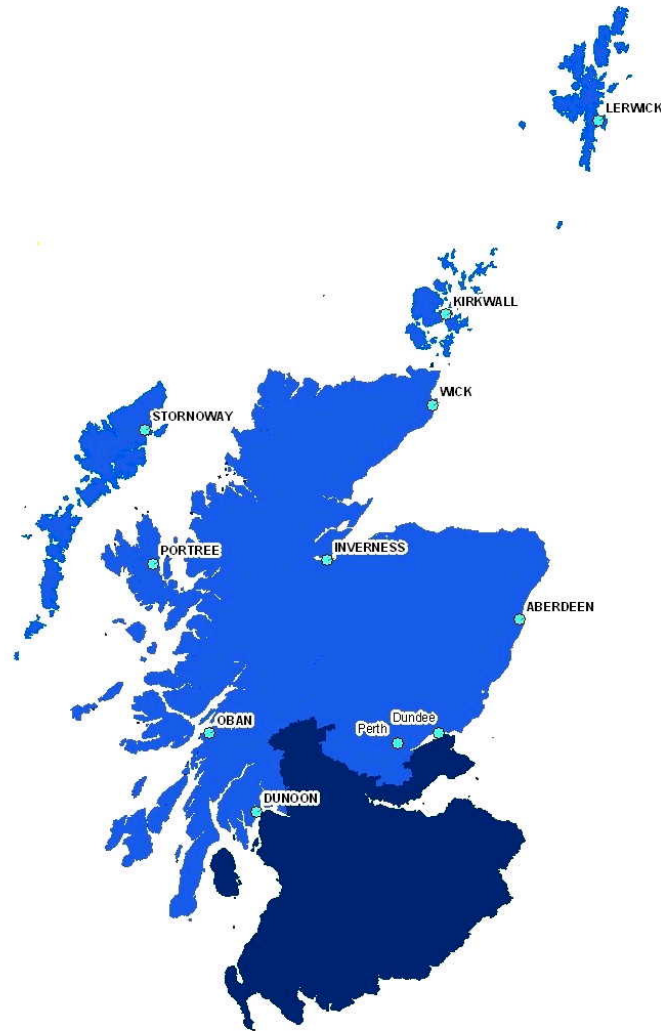


**NORTH OF SCOTLAND  
PLANNING GROUP**



**NeSCANN Annual Report 2011**

**North Scotland Child and  
Adolescent Neurology Network**

# NeSCANN

North Scotland Child and  
Adolescent Neurology Network

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## 1. Introduction

### Clinical Lead – Dr Martin Kirkpatrick

Welcome to the 2011 Annual Report from the North Scotland Child and Adolescent Neurology Network. While there have been reports in the past, these have been of an informal nature and the fact that this is a formal report reflects that very welcome administrative and management support that is now afforded to our clinical service network. In particular Carolyn Duncan has joined us as Network Manager and this has allowed us to cement some of the developments that have been taking place over recent years.

The recent National Delivery Plan investment has been crucial in those developments and has been the first major investment in the Network since its inception nearly 10 years ago. One of the principles in the bids that went forward was that to sustain a tertiary service there needs to be investment in both tertiary and secondary services. No tertiary service can function in isolation from secondary level services – there has to be someone to network with!

It is of course important to be able to demonstrate that this investment results in improvement in quality of services. Outcomes such as counting operations or re-admission rates are clearly not relevant to paediatric neurology and the logic model has been one way of demonstrating those quality improvements.



Dr Martin Kirkpatrick, Carolyn Duncan

## **Network Manager – Carolyn Duncan**

I commenced in the Child Health Network Manager post (part-time) in December 2010, working closely with Dr Kirkpatrick and supporting all members of the North Scotland Child and Adolescent Neurology Network (NeSCANN) in Aberdeen, Dundee and Inverness. I am also Network Manager for the North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition and Paediatric Respiratory networks.

2011 has been a very busy and interesting year. I made contact with staff involved in the network across the North and built up my knowledge on all that had taken place historically with the network since its inception and during the National Delivery Plan process. My supporting role is very varied, challenging and interesting and I am very fortunate to work with so many experienced, dedicated, highly motivated staff. My work has included being involved in the establishment and running of the network steering group, writing the work plan, input to the NDP evaluation report, the Epilepsy Specialist Nurse Training and Education group, the Moray Epilepsy service, data collection and IT systems.

This is our first formal NeSCANN report and I hope you find it interesting and informative. I look forward to supporting the network with enthusiasm and commitment in 2012.

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

Dr Kirkpatrick and Carolyn Duncan are members of the North of Scotland Child Health Clinical Planning Group (CHCPG) and Clinical Leads' Group. The CHCPG takes place 4 times per year, with the first meeting of the Clinical Leads' Group taking place in autumn 2011. The CHCPG drives forward the strategic aims of child health networks in the North in line with national drivers and initiatives. 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.

It is the intention that a representative working on behalf of patients and families in the North will become a member of the CHCPG in 2012.

## 2. Background to the Network

The North Scotland Child and Adolescent Neurology network (NeSCANN) supports children with epilepsy, neurological and neurodisability conditions across 5 Health Board areas in the North of Scotland. The network commenced informally in 2002 with tertiary out-patient clinics in Aberdeen and Dundee carried out by Tayside Children's Hospital Consultant Paediatric Neurologists and has evolved and grown over the past 10 years to include out-patient services in Inverness, Orkney and Shetland.

Childhood epilepsy accounts for approximately 50% of paediatric neurology practice.

The network provides a specialist tertiary service, working in close collaboration with secondary care paediatric staff and services in 3 main centres, where in-patient facilities are also provided. They are,

Royal Aberdeen Children's Hospital  
Tayside Children's Hospital, Ninewells  
Raigmore Hospital, Inverness

Multi-disciplinary teams are based in all of the above where services include out-patient clinics, investigations and treatment. Tertiary clinics in the Islands have been further developed by Dr Kirkpatrick and Dr Alice Jollands (Consultant Neurologists) and enhance locally delivered patient care in Orkney and Shetland.

Regular quarterly network NeSCANN project team meetings became formal network Steering Group meetings from March 2011, when the structure and membership of the group going forward were agreed. A work plan was written and agreed, highlighting the following objectives for the network in the next couple of years:

- Formalise a Paediatric Neurology Steering Group
- Establish safe storage for clinical video and photography
- Increase VC consultations with patients in remote location
- Map, develop and agree care pathways
- Develop information for patients
- Implement a cross-boundary data collection IT system
- Continue to develop the network education framework
- Develop a universal standard of training and education delivered by Epilepsy Nurse Specialists across the region
- Audit clinical care

In addition, monthly multi-disciplinary team meetings take place in Aberdeen (Neurology Open Day) and Dundee (Brainwave), providing forums for discussion on complex cases, developments, brain imaging and neurophysiological investigations. A similar forum is developing in Inverness alongside the clinics from the visiting tertiary Paediatric Neurologists.





Back row: Dr Ann O'Hara, Dr Martin Kirkpatrick, Dr Ayaz Shah, Dr Bruce Downey  
Front row: Dr Elma Stephen, Dr Alice Jollands, Ena Cromar



Jan Rosie, Dr Alan Webb, Dr Linda MacLellan, Dr Lesley Henderson, Dr Patrick Fox



Pauline McEachen, Sheila Kerr, Karen Lawrence

It was not possible to capture everyone, therefore some staff are missing from team photographs.

### 3. National Delivery Plan

National Delivery Plan funding from 2008-2010 provided significant investment to enhance the work of the network. Additional posts were recruited to in each of the 3 main centres in order to provide equitable, timely access to the best services for children and adolescents with complex neurological conditions across the North. Multi-disciplinary teams of staff deliver services as locally as possible to patients' homes e.g. doctors, Epilepsy Nurse Specialists, Ketogenic Diet Co-ordinator, Neuropsychologists, Physiotherapists, Speech and Language Therapists and Occupational Therapists. Funding also provided Clinical Lead (2 PAs) and Network Manager support (0.4 WTE), however the Network Manager post was not recruited to until December 2010.

While many of the new posts are hosted within an individual Health Board, they work across the region to support the work of NeSCANN.

Years 1 to 3 funding has helped to facilitate:

- 0.5 WTE Specialist Epilepsy Specialist Nurse posts in each mainland Health Board to enhance and improve services delivered close to home for children with epilepsy.
- Tertiary support to neurology clinics in Orkney and Shetland.
- The further development of integrated paediatric neuromuscular services in Aberdeen, Dundee and Inverness. This has significantly reduced the need for families to travel to neuromuscular centres in Newcastle and London.
- A Ketogenic Diet Co-ordinator, who has been providing
  - Ketogenic diet clinics
  - Ketogenic diets for individual patients
  - Training to existing dietetic staff across the network to be able to provide new and existing patients with ketogenic diets.
- Enhanced Neuropsychology services for Aberdeen, Dundee and Inverness.
- Consultant post in Highland to include general paediatrics as well as a special interest in epilepsy for Highland and Moray.
- Recruitment of a Physiotherapist with a special interest in Intrathecal Baclofen.



#### **4. Logic Model**

A significant piece of work was carried out with the North of Scotland Public Health Network in 2010/11 to produce a logic model for the network (update at Appendix 1). The NeSCANN logic model approach has provided a description of how the service works and considers things such as the evidence base for the service and patient needs. It highlights network activities and resulting benefits and the outcomes that the service will continue to achieve, for example:

- Patients have access to the best possible services as locally as possible
- Travel times for patients and families are reduced
- Families have improved experiences of health services
- Staff have access to high quality peer support in the network
- Families are supported and empowered throughout their child's illness.

The logic model supported the development of the network through the implementation of NDP funding and remains a working document providing focus on the aims of the network and the ongoing work in relation to the work plan.

## **5. Workforce**

2011 has been very busy with the expansion of services and the coming together of multi-disciplinary teams in each of the 3 main centres. Increased numbers of Epilepsy Specialist Nurse and Neuropsychologist posts in each of the 3 main centres is now providing an enhanced service to patients and improved quality of care.

### **Arrivals**

The ability to recruit to a 10 PA post of Consultant Paediatrician with a Special Interest in Epilepsy, covering Highland and Moray had been challenging and NDP funding had been available in 2009. The network was pleased that Dr Alan Webb, Consultant Paediatrician at Raigmore agreed to take up the post at the end of 2011 and he will be supported by the Epilepsy Specialist Nurses.

The following staff also joined the network during the year:

Ena Cromar, Epilepsy Specialist Nurse, RACH  
Kirsteen Mackintosh, Epilepsy Specialist Nurse, Raigmore  
Dr Tracy McGlynn, Psychologist, Raigmore  
Dr Rachel Smith, Psychologist, Raigmore  
Jo Thomas, Occupational Therapist, RACH

Staff involved in the delivery of the network is attached at Appendix 2.

### **Vacancies**

Recruitment to the Aberdeen Physiological Technician NDP post has been challenging (funding shared between Gastroenterology, Neurology and Respiratory), with ongoing discussions as to the most appropriate use of the funding in NHS Grampian. It was felt more beneficial to patients that the neurology portion of the funding be used to develop a video telemetry service (VTEM) at RACH. Dr Ayaz Shah is collaborating with paediatric and adult service colleagues in order to make this happen.

## **6. Network Activities**

### **6.1 Steering Group**

The NeSCANN steering group was formalised in March 2011 following the appointment of the Network Manager. The group met virtually in March, June and October with very good attendance from Aberdeen, Dundee and Inverness. Membership in 2011 included representation from medical, nursing and Allied Health Professionals as follows:

Dr Martin Kirkpatrick	Consultant Neurologist
Carolyn Duncan	Network Manager
Dr Alice Jollands	Consultant Neurologist
Dr Ayaz Shah	Consultant Paediatrician
Dr Alan Webb	Consultant Paediatrician
Dr Ann O'Hara	Associate Specialist
Jo Campbell	Epilepsy Specialist Nurse
Jan Mackenzie	Epilepsy Specialist Nurse
Kirsteen Mackintosh	Epilepsy Specialist Nurse
Ena Cromar	Epilepsy Specialist Nurse
Karen Lawrence	Epilepsy Specialist Nurse
Pauline McEachen	Epilepsy Specialist Nurse
Helen Grossi	Ketogenic Diet Co-ordinator
Dr Elma Stephen	Consultant Paediatrician
Dr Linda MacLellan	Consultant Paediatrician
Dr Lesley Henderson	Consultant Paediatrician

Various network and North of Scotland Planning Group operational issues have been discussed, including staffing, service developments, NDP reporting, training and education, work plan, IT systems, equipment and audit. It is intended that membership of the group will be reviewed early in 2012 to include a member from neuropsychology.

### **6.2 Clinics**

The range of additional medical, nurse-led, neurophysiological, neuropsychology and dietetic clinics commenced in 2010 by way of NDP funding continued to be built on in 2011. Moray Epilepsy clinics will also commence in January 2012. Children and adolescents with complex neurological conditions now have improved timely access to specialist neurology and epilepsy multi-disciplinary services provided by skilled, experienced staff as close to their homes as possible.

Tertiary clinics in the Islands continue to enhance locally delivered patient care by Consultant Neurologists in Orkney (twice per year) and Shetland (3 per year). In addition follow-up clinical consultations with Orkney patients are carried out by video-conference twice per year.

Access to comprehensive clinic data continues to be an issue for all child health networks across the North of Scotland. It is hoped that with the adoption of the NSD Clinical Audit System by NoSPG in the coming year that timely, easy accessibility to useful network patient information will be possible.

### **6.3 Work Plan**

A network work plan was drafted by the Network Manager and Clinical Lead and agreed by the Steering Group during the year. The work plan at December 2011 is attached at Appendix 3 and is being performance managed by way of a traffic light system, i.e. Red/Amber/Green status.

Some work plan objectives were met in 2011, with others advancing well. They will continue to be reviewed and developed according to service need in 2012. As with other child health networks, data management and audit and the adoption of a fit for purpose IT system that can be accessed from anywhere in the North is still high on the agenda. In this respect, discussions have taken place jointly with the Scottish Paediatric Epilepsy Network and the NSD Clinical Audit System developer in order that appropriate data fields are set up to ensure accurate, timely data collection and audit capabilities for the benefit of the service and network patients.

#### **6.4 Training & Education Framework**

Significant progress has been made in the area of training and education with the development of the network training and education framework and standardisation of Epilepsy Specialist Nurse training and education standards.

The Epilepsy Nurse Specialist Training and Education Group set up during 2011 has been working hard to standardise the disease and treatment information provided to patients and families and the delivery of training provided to families, medical, social care and education staff across the region.

A successful 2011 NeSCANN training needs survey, distributed to tertiary and secondary care clinicians across child health specialities in the North provided valuable information from 58 clinicians as to their wishes for future network education and training opportunities. This is being used to inform future planning.

#### **6.5 Multi-disciplinary meetings/Teaching sessions**

Monthly multi-disciplinary meetings take place in the 3 main centres i.e. Brainwave (Ninewells), Neurology Open Day (RACH) and Raigmore lunchtime sessions, which provide regular teaching and educational forums for learning. In addition, a monthly bulletin of local, regional and national neurology educational opportunities accessible to all staff is published and circulated across the North of Scotland.

#### **6.6 Telemedicine and Video-Conferencing**

Regular video-conferencing consultations continue to be carried out across the network reducing the need for patients and families to travel to the mainland for clinical consultations. Some clinics in Orkney and Shetland have been run entirely via video-conference. While this clearly can never be an entire substitute for a "face-to-face" clinic there are times when then this can be an effective and efficient way of delivering clinical care.

Some excellent examples of the benefits of telemedicine for patients in remote areas, where care or advice is able to be delivered locally, took place during the year:

- A patient with severe refractory epilepsy had a history of being transferred to the mainland due to prolonged seizures. However through collaboration of professionals, the exchange of expert knowledge and the implementation of an individualised patient management plan, during the patient's last Island hospital admission, local A&E staff were able to be supported by specialist staff using video-conferencing. This resulted in the patient being treated locally and they did not need to be transferred to the mainland.
- Immediate parental advice given - One of the Children's Epilepsy Specialist Nurses was able to hold lengthy face-to-face discussions over video-conference with the parents of a complex epilepsy patient close to their home, who had major concerns with a change in their child's medication. Their fears were able to be allayed without having to wait until their next clinic appointment and they felt more confident and empowered in being able to deal with their child's condition.

## **6.7 Communications Plan/patient information/website**

A draft Communications plan is in place to outline a communication strategy for the network and to identify all stakeholders associated with NeSCANN. The plan details the routes of communication between steering group members and the health board areas they represent, leads of sub-groups and workforce and regional planning.

### **Website**

It was agreed at the North of Scotland Planning Group that web pages for NeSCANN, as with other child health networks, will be set up on the NoSPG website in future. This will be progressed in 2012 and it is intended that standard guidelines, protocols and care pathways will be uploaded for staff reference, which will be password protected.

## **6.8 Liaison with national/regional Managed Clinical Networks**

The network was delighted when Dr Ann O'Hara, Associate Specialist from Royal Aberdeen Children's Hospital, was appointed to the Lead Clinician role for the national Scottish Paediatric Epilepsy Network (SPEN) in December. This will further strengthen established network links with SPEN.

We are now part of the Scottish Paediatric Epilepsy Surgery network. We participate in monthly multi-disciplinary team meetings, organised with video-conferencing facilities, so that children with epilepsy who may be suitable for epilepsy surgery can be considered in an appropriate multi-disciplinary forum. The surgery itself will be centralised in one venue in Scotland but the assessment takes place on a Scotland-wide basis.

There are also strong links with the Scottish Muscle Network with clinicians being closely involved in developments and service improvement updates.



## **7. Key Service Developments**

### **7.1 Moray Epilepsy Service**

High level discussions between NHS Highland and NHS Grampian management and clinicians have taken place with regards the future arrangements for Moray epilepsy patients, following the confirmation of Dr Alan Webb as Consultant Paediatrician with a Special Interest in Epilepsy.

A planning meeting hosted by the North of Scotland Planning Group took place in Elgin in December, which was well attended by clinical and managerial staff from NoSPG, NHS Grampian, NHS Highland, the Scottish Ambulance Service and the network. The first joint clinic was subsequently planned for January 2012, supported by the Epilepsy Specialist Nurses, with quarterly joint clinics being provided in the first instance. Additional clinics will be developed in due course following appointment to a vacant Consultant Paediatrician post in NHS Highland.

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. Referrals, out-patient and in-patient services, patient transfers, caseload and case scenarios were discussed in great depth. It was also agreed that getting transition arrangements correct for the clinic and patients over the coming year will be extremely important. Dr Webb will liaise with Dr Elma Stephen, Consultant Paediatrician, regarding future service provision and assistance from network Consultant Neurologists at Elgin clinics will be provided wherever possible.

### **7.2 Epilepsy Specialist Nursing**

The role of the Epilepsy Specialist Nurses generally follows the wider role of the specialist nurse generically and includes:

- support and information for the patient, carer and family
- provision of up-to-date, accurate and relevant information and advice
- support and information for the multi-disciplinary team involved in the patients' care
- education for statutory and voluntary organisations and a source of expert knowledge
- more specific roles include adjusting medication, ordering relevant tests and patient review on return clinic visits. (*Ref. SIGN 81*).

NDP provided additional 0.5 WTE Specialist Epilepsy Nurse posts in NHS Grampian, NHS Highland and NHS Tayside, with the postholders working with nursing colleagues to establish their roles during the year. This has brought great benefits to the patients and to the service as a whole with a huge amount of work being carried out collaboratively across the region.

### **7.3 Epilepsy Nurse Education and Training**

The Epilepsy Specialist Nurse training and education sub-group was set up during the year led by Dr Jollands, with the aim of providing a framework and of setting generic standards for training and information provided by the nurses to:

- Patients, families, carers
- Non-health professionals including teachers, school auxiliaries, social care staff
- Health professionals including nurses, doctors and Allied Health Professionals.

General principles were agreed with regards to the type of written information that is provided, whilst bearing in mind the recommendations of the Scottish Intercollegiate Guidelines Network, SIGN 81 guideline 'Diagnosis and management of epilepsies in children and young people'.

Topics and information discussed to date have included:

- Age appropriate information packs
- Emergency/rescue medications
- First Aid seizure training
- Administration of Buccal Midazolam
- Patient Information Leaflets
- Epilepsy awareness training
- Seizure recognition for night staff.

A draft framework document is nearing completion, which provides excellent evidence of how good communication, collaboration and team working is taking place across the region for the benefit of staff, patients and families. The document will be widely distributed in due course.

## **7.4 Teenage Epilepsy and Transition Clinics**

Regular epilepsy clinics for teenage and adolescent patients who transition from paediatric to adult services take place across the region:

### **NHS Highland**

- Annual adolescent Transitions Epilepsy clinic in Inverness involving a Community Paediatrician, adult Neurologist and Specialist Nurses.

### **NHS Tayside**

- Three Teenage Epilepsy clinics per month (age 12 upwards) led by a Consultant Paediatrician and Epilepsy Specialist Nurse are held in Dundee.
- Two adolescent Transitions Epilepsy clinics per year are held, involving a Consultant Paediatrician, adult Neurologist and Specialist Nurses.

### **NHS Grampian**

- Teenage Epilepsy Specialist Nurse led clinics 6 times per year.
- Two Transitions Epilepsy clinics per year involving a Consultant Paediatrician, adult Neurologist and Specialist Nurses.

## **7.5 UPDATES FROM NEW NDP FUNDED POSTS**

### **7.5.1 Epilepsy Specialist Nurses**

#### **Dundee - Epilepsy Specialist Nurse Update - Pauline McEachen**

Since Pauline commenced part-time in the post of Epilepsy Nurse Specialist, the following developments have been organised to improve and work towards a 'gold standard of care' for children and teenagers diagnosed with epilepsy and to compliment and enhance patient care in Tayside and include -

- Developing and organising monthly 'Epilepsy Awareness and First-Aid Management teaching' sessions held in Perth Royal Infirmary, Perth and Ninewells Hospital, Dundee to provide an equitable and sustainable service in improving the knowledge and skills of staff caring for children/teenagers diagnosed with epilepsy, i.e.
  - Non-healthcare staff in schools, nurseries and voluntary sectors
  - Professional staff in acute and primary care settings
- Medication audit to identify GPs, community Pharmacists and the hospital Pharmacist in ensuring provision of,
  - the correct medication
  - the correct dose and

- sufficient supply of patients' medication.
- Enquiring if families are,
  - keeping old stock of medication in their homes
  - checking the medication is in date
- Auditing emergency Buccal Midazolam medication to find out,
  - whether the young person has been seizure free for 2 years
  - whether the parents know how to administer the medication and
  - when they had their last update on how to administer the medication and if so from whom.

### **Inverness – new Epilepsy Specialist Nurse Role – Kirsteen Mackintosh**

I came into the part-time post of Epilepsy Specialist Nurse in August 2011. It has been a great experience to date working with such skilled staff and under the excellent guidance of Jan Mackenzie. The team has noticed a definite decrease in hospital admissions and received continuous positive feedback about the service from patients and their families. We have been able to assist Dr Webb in developing a bi-monthly clinic for Highland patients and in extending our peripheral clinics to Fort William, Caithness and Elgin. We are now able to provide dedicated, timely support and care for our patients as close to their homes as possible.

The service in Inverness has developed significantly due to NDP funding and I am enjoying assisting in improvements to patient care. As my confidence grows I may even lead in the implementation of new developments! I am looking forward to attending the PET 1 course in June 2012 and I will also continue on to the PET 2 course in October. A busy year ahead!

### **Aberdeen - A new Epilepsy Specialist Nurse perspective – Ena Cromar**

I joined the Neurology in team in Aberdeen as an Epilepsy Specialist Nurse in February 2011 working 18.75 hours per week. When I came into post I was given the opportunity of a three month induction period, this allowed me to shadow Jo Campbell giving me an insight into the role of the Epilepsy Specialist Nurse. I was also able to visit the Epilepsy Specialist Nurses in Glasgow, Dundee and Inverness; this was a very useful networking opportunity and allowed me to see how the epilepsy service in their area worked. I attended the neurology clinics held at the Royal Aberdeen Children's Hospital where I was able to be introduced to the children, young people and their families on our caseload. The introduction of another Epilepsy Specialist Nurse was met with very positive verbal feedback from parents.

Over the past year more than 70 new children and young people were diagnosed with epilepsy, making our current caseload around 500. Since I have been in post we are able to offer all newly diagnosed children and young people a home visit if they wish. We may also be asked by nurseries and schools attended by children and young people with epilepsy to give talks to staff on epilepsy awareness and first aid. If children have been prescribed emergency medication for prolonged seizures we will give training to parents, carers, nursery and school staff on how medication is administered. Now I am in post the service provision is better covered during the working week and holiday periods. There are no longer long periods of time when a Specialist Nurse is unavailable for advice or support, ensuring the service is more accessible to families and provides improvements in patient care.

An example of a family who accepted the offer of a home visit is a family of a 4 year old who initially presented with generalised tonic clonic seizures lasting 2-4 minutes. He then went on to develop myoclonic seizures and atonic seizures and because of the evolving symptoms and the potential diagnosis of an epilepsy syndrome his parents asked for a visit to discuss his condition and safety issues around his seizures. He has a safety helmet he wears at nursery for protection if he has an atonic seizure. I also went to the nursery he attends and spoke with the nursery

staff about his epilepsy and first aid. The child is currently on 3 anti-epileptic medications and has had further prolonged generalised tonic clonic seizures, for which he is now prescribed emergency medication. I have given parents training in the use of the emergency medication and will be carrying out training for nursery staff. We receive weekly updates from his parents on his seizures which are very useful. This also gives a chronological record of his symptoms and assists the team with advice and support required with ongoing changes.

Every 2 months we hold an epilepsy link nurse meeting. This meeting is to update staff on conditions, guidelines, treatments and training. A nurse from each area within Combined Child Health, Orkney and Shetland is invited to attend. The nurses who attend have an interest in epilepsy and actively feedback information to their department from the meetings. Thinking of succession planning, it is hoped these meetings will give nurses outwith the team an insight into the role of the Specialist Nurse, who may wish to develop into this type of role in future.

## **7.5.2 Neuropsychology**

Enhanced neuropsychology input is now being provided in Grampian, Highland and Tayside due to NDP funding. This means that NeSCANN now meets many aspirations and recommendations by national bodies such as SIGN, NICE and the Scottish Government and Department of Health best practice guidelines.

### **Aberdeen**

Dr Bruce Downey provides specialist diagnostic assessment and treatment to children and adolescents presenting with cognitive, behavioural or educational change in the context of actual or suspected neurological illness or injury. He has recently gained a British Psychological Society accredited qualification to allow him to undertake complex neuropsychological assessments and produce formulations and intervention programmes with children who have an Acquired Brain Injury (ABI). He works in close collaboration with medical, nursing, Allied Health Professional and education staff across the region and has a vital role in the pathway between the management of children in acute or primary care through to integration within community and education settings.

NDP funding has enabled the service in Grampian to provide more timely neuropsychological input to children with both developmental and acquired brain disorders from the age of 5 to the end of full-time education. Other developments that have been made possible over the past year are as follows:

- Doubled the amount of neuropsychology out-patient clinics.
- Increased neuropsychological consultations to colleagues.
- Reduced neuropsychology waiting times to less than one month.
- Regular attendance at local neurology and Epilepsy transition clinic team meetings.
- Attendance at a 3-monthly combined neurology, endocrine and oncology clinic.
- Facilitate a nurse supervision group.
- Develop agreed protocols for paediatric acquired brain injury patients.

### **Inverness**

This is a new service for the neurology network in Inverness. Dr Tracy McGlynn and Dr Rachel Smith are consulted by Paediatricians on a case by case basis. They attend weekly Children's Ward psychosocial meetings and offer a drop-in consultation clinic which allows timely access to psychological services.

Follow-up cognitive assessments, after completion of radiotherapy and chemotherapy have been undertaken as part of the oncology clinic. This has occurred after liaison with Clinical Psychologists in other hospitals who provide the initial baseline assessment prior to

commencement of treatment. A new paediatric head injury pathway has also been developed. This provides a clear framework for best practice and clearly identifies a role for psychology.

Community nursing staff and allied health professionals working in both areas attend a monthly reflective practice group held by the Psychologists. This provides a forum to offer a psychological perspective for those working in a predominantly medical model.

They have been trained to deliver the NHS Education Scotland training; Psychosocial Interventions for Improving Adherence, Self-Management and Adjustment to Physical Health Conditions for Children and Young People. One of three scheduled training days has been completed, with further dates to be arranged.

### **7.5.3 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 clinical staff and patients with complex epilepsy, who have failed on two or more anti-epileptic medications. 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.

In the North of Scotland, a total of 13 patients are currently on a ketogenic diet, with 4 patients who were on the diet as part of their treatment regime recently coming off it. Advice was also provided to 4 patients and families, who did not wish to proceed with going on the diet.

In addition Helen has delivered 5 training sessions in Grampian, Highland and Orkney to update dietitians and nursing staff. This has also enabled the upskilling of local Dietitians to be able to deliver ketogenic diets to patients as close to their homes as possible. She has also provided 9 useful training and awareness sessions to education and social care staff across the NeSCANN region, so that they are fully aware of the needs of this patient group.

A total of 8 ketogenic diet clinics continue to work well across the North i.e. 3 in Grampian, 3 in Tayside and 2 in Highland.

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.

### **7.5.4 Physiotherapy**

Funding has been provided for three part-time posts to enhance network neurology physiotherapy services supporting patients with neuromuscular conditions and those requiring Intrathecal Baclofen.

Anne Keddie works in Tayside, Jane Tewnion in Grampian and Jo Armstrong, working with patients requiring Intrathecal Baclofen.

Patients and families are supported as well as local therapists and clinicians by giving advice and training as close as possible to patients' homes or educational settings. In addition, it has also recently been possible to include patients and families with Spina Bifida in the Grampian service. Staff also attend local and national network meetings to keep up-to-date with service provision and practice and for peer support and continuing professional development.



## **Intrathecal Baclofen Physiotherapy – an update from Jo Armstrong**

I have been in post as the ITB Physiotherapist for North of Scotland for just over a year. I have been involved in joint assessments at muscle tone management and ITB clinics in NHS Tayside alongside Dr Kirkpatrick, Dr Eunson and Dr Naismith, for children with more challenging muscle tone issues. I have carried out the specialist physiotherapy assessment in 3 ITB trials in 2011, involving 2 children from Tayside and one from Grampian and have been involved with the Multi Disciplinary Team in the decision-making following trials of whether pump implantation should be recommended. Over the last year my knowledge and skills in the area of tone management have dramatically increased. I have worked jointly with Physiotherapy colleagues in Tayside looking at specific outcome measures, from both a teaching and learning perspective e.g. the modified Ashworth scale, GMFM (Gross Motor Function Measure).

I was fortunate to attend the National ITB forum in Birmingham and I also have established myself as a member of the National ITB Physio Forum, which is a group of Physiotherapists who work within ITB services across the UK, covering both paediatrics and adults. The group meets bi-annually to discuss current issues and we are currently working on a Physiotherapy appendix to the National ITB document, which will establish best practice guidance for Physiotherapy in ITB. I have also established a good working relationship with the Physiotherapist involved in ITB at Edinburgh Sick Children's Hospital.

During 2012 I will be providing presentations on ITB therapy and the role of the Specialist Physiotherapist in ITB to a variety of professionals. I will continue to work on collaborating with colleagues across the North of Scotland by attending clinics in Aberdeen and Inverness and getting to know the local Physiotherapists in these areas. I would also like to compare differences in practice in other UK centres to identify potential quality improvements that could be made to the current regional service for patients, their carers and our network professionals.

## **Neuromuscular Conditions - Update from a Clinical Specialist Physiotherapist**

I have now been in post as Clinical Specialist Physiotherapist in Paediatric Neuromuscular Conditions for the North of Scotland for a year. I have fulfilled many of my first year goals, which encompassed Education, Audit and Specialist Assessment. My greatest achievement has been in education, in my own CPD and in teaching and advising others.

I have attended national conferences, national NM database clinical networks meetings, Scottish Muscle Network (SMN) paediatric sub-group meetings, SMN paediatric physiotherapy sub-group meetings and boosted my library of NM articles as well as keeping abreast of new studies etc. I initiated and chaired the first local NM interest group for Dundee and Angus.

I have given presentations on conditions and how to care for the children to seven local schools and attended and given advice at twelve clinics in the north east. I have helped organise and run NM respiratory study days for Scottish physiotherapists. I started working towards equity of physiotherapy input throughout Scotland by compiling a database of children with NM conditions receiving physiotherapy in the North of Scotland and had discussions with the two therapists with NM interest in Grampian and Highland. I am monitoring and evaluating existing practices and using national evidence and pathways to develop the service and identify where support is required. I am part of a small team who devised and audited the Duchenne Muscular Dystrophy (DMD) Scottish Physiotherapy Management Profile. I input my assessment data to the North Star and Smartnet national databases. I have taken responsibility for piloting Transition Folders with young people in the north east. I have kept my local NM caseload to improve my knowledge and skills and enjoy carrying out specialist assessments to help with diagnosis.

Over the next year I plan to continue to increase my own knowledge and roll it out to other multi-professional groups, audit the Physiotherapy Pathways and work closely with the other regional Physiotherapists in our quest to gain best practice throughout Scotland.

### *Benefits of My Post*

One of our local mainstream primary schools has four boys of varying ages with DMD that required a lot of physiotherapy input. I devised activity programmes for the boys which could be carried out by school staff however this was met with a degree of resistance. I realised that the main problem was a lack of confidence and understanding of the condition throughout the school staff and not the usual time shortage and staffing issues. Junior and care staff did not seem to be getting sufficient support from senior staff, despite me going into school weekly and giving advice. I arranged to give a twilight presentation to a large number of support and teaching staff of all levels. I covered some basic pathology, the problems the boys with DMD face and most importantly, strategies for dealing with them. The evaluation forms were very encouraging and the whole school situation is now much more positive as they feel less threatened by a condition they did not understand. The staff now carry out an activity programme with all four boys on a daily basis and call me occasionally for advice.

In summary, a 1½ hour presentation has led to the boys having daily “physio”, the staff feeling confident and happy and my input markedly reduced. There is also less stress as the families know the boys are having their physio in school. This new post and service therefore demonstrates a great improvement in quality of care, a service delivered locally and empowerment of school staff to ensure the best physiotherapy service possible for the benefit of these children.

**Anne Keddie**

#### **7.5.5 Speech and Language Therapy – Winnie Taylor**

Due to NDP funding involvement with the Acquired Brain Injury network group in Grampian, as well as linking in with national MCN meetings, have been possible. Members of the local paediatric group have agreed that in developing their skills and pathways for these patients that they will meet and present on individual input to patients retrospectively. This will allow individuals to look at improvements to practice and to increase communication within the group. Referrals have been received from Paediatricians as follows:

- One off assessment of communication status to inform differential diagnosis.
- Assessment and ongoing therapy.
- Assessment and transfer of a child to an appropriate local therapist.
- A second opinion.

Following the assessment a report is sent to the referring clinician. The additional sessions have meant that patients are seen almost immediately for assessment and treatment.

## **8. Patient Stories**

### **8.1 John's Story**

*The name of this patient has been changed to preserve anonymity.*

John, a 13 year old boy, living half way from Inverness to Wick, is seen in the local clinic in Golspie. He has been having progressive difficulties with unsteadiness and falls and his speech seems to have deteriorated slowly over a number of years. He is subsequently seen in the Inverness clinic and then referred on to the joint tertiary neurology clinic held twice a month in Inverness. It is clear that John has worsening skills and he is now being significantly affected by this condition. One of the possibilities is that this is a metabolic disorder that, importantly, may have genetic implications and may be amenable to treatment.

All the necessary investigations and tests are performed locally with those blood samples requiring highly specialised analysis being sent away, in this case to a national centre in Manchester. The definitive diagnosis of a specific very rare metabolic disorder is confirmed.

Since there is a specific and expensive treatment for this condition, John is referred to the Willink Biochemical Genetics unit in Manchester to see whether John would be a suitable patient to start on that treatment. Following this, criteria for treatment are agreed, funding is sought from NHS Highland and daily treatment commenced. It is hoped that this treatment will slow down or halt the progression of this disease for a number of years. The costs of the drug are high but are offset against the costs of looking after John's likely increasing needs as the disease otherwise progressed untreated. In addition, support by telephone and email as well as two visits to John's home by the national Specialist Nurse for this condition based in Manchester who has been pivotal in supporting both John, his family and the local clinicians.

Other than a single trip to Manchester, John and his family have needed to travel no further than Inverness. His diagnosis, treatment and further management will all be coordinated and managed from within local NHS Highland services. We believe this is one of the successes of clinical service networks – we bring that expertise to the patient; rather than the patient making multiple, hugely long, time-consuming journeys to the service.

### **8.2 On Island Ketogenic Diet Support**

I recently had a patient referred to the service who lives in Orkney. The Paediatric Dietitians based in Orkney were not trained in being able to deliver ketogenic diets locally.

The decision was taken that I would visit Orkney to provide staff training and to support the family. During the visit I was able to meet the child and her parent in the home setting, which made things easier regarding advice on cooking facilities etc, and being able to reassure the parent that she would have local support, even although they live in a remote area. As well as visiting the patient at home, I visited the Respite Centre that the child attends regularly and was able to advise and train the local staff on the implications and practical aspects of the diet. Members of staff from the child's school were also able to attend this session, which was very helpful.

In addition, I provided a Ketogenic Diet training session for the local Paediatric Dietitians, the child's GP and the nurses to enable them to provide support for the child and her family in a local setting. It is intended to hold further training sessions when required using video-conference technology.

My post of Ketogenic Diet Coordinator enables me to visit remote areas and to provide a training service to local health and social care staff. This makes a considerable difference to the family's ability to follow what is a complicated treatment. It also increases the knowledge and skills of the local staff and empowers them to be able to deliver a specialist service locally.

**Helen Grossi**

## **9 Key Challenges**

### **9.1 Workforce - Doctors in training**

NeSCANN wishes to support doctors in training whether they are aiming to become Consultants with an interest or tertiary Paediatric Neurologists. Teaching opportunities for doctors are available through video-conference presentations and monthly local network educational opportunities in each of the 3 main centres as well as other local and national events such as those organised through the British Paediatric Neurology Association (PET1 and PET2).

### **9.2 IT/HR/Governance**

A major challenge for NeSCANN is the management of patients who have to move across health board boundaries to receive treatment. Historically IT and results systems have been designed to work only within a given health board and most 'do not speak to each other'. While work is ongoing to integrate SCI stores across health boards this is not yet working.

National Services Division (NSD) has funded the development of the Clinical Audit System that has been designed to support specialist paediatric services in Scotland, initially through the national Managed Clinical Networks. The Scottish Paediatric Epilepsy Network (SPEN) is well advanced in adopting the system and NeSCANN members have been involved in discussions so that the needs of patients in the North are included in SPEN's dataset. It is hoped that progress will be made in the North so that NeSCANN and other regional child health networks can make use of the system starting in 2012.

At present staff working across more than one health board need multiple contracts and multiple health and security checks. Clinical governance responsibility also sits within individual health boards. Work is ongoing to simplify this process and ensure that staff have the confidence and support to work in a seamless manner across the North where it is clinically required. In addition, there has been a significant amount of work carried out in the North of Scotland Planning Group in relation to a regional clinical governance framework, which continues to be developed in liaison with Health Improvement Scotland.

## 10. Research & Audit

### 10.1 'Epilepsy 12'

NeSCANN clinicians have been closely involved in a national audit of the care of children with newly diagnosed epilepsy. This 3 year audit will be completed in September 2012 and will give 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. Members of NeSCANN were one of 3 "early adopter" sites and the UK patient experience questionnaire was developed by members of NeSCANN in collaboration with the University of Dundee.

Members of the network have been involved in presentations to scientific meetings and published papers on epilepsy and movement disorder genetics, SUDEP and neuropathies.

### 10.2 Re-audit of the Children's, Epilepsy Specialist Nurse Service at Royal Aberdeen Children's Hospital -June 2011

SIGN (Scottish Intercollegiate Guideline Network) Guideline 81 – 'Diagnosis and management of epilepsies in children and young people', recognised the value and contribution of a dedicated Epilepsy Specialist Nurse (ESN) for children and their families and recommended that each epilepsy team should include such a post. An ESN post was established in February 2004 in NHS Grampian and the first Audit of the Children's ESN Service took place in 2005. Following implementation of the action plan a re-audit to measure the impact of change took place in 2010.

#### Method

The questionnaire used in 2005 was adapted using SNAP TM (Optical Recognition) Software. Questionnaires were given to parents of children and young people attending for out-patient epilepsy review clinic appointments from February to October 2010. Completed questionnaires were returned to the Clinical Effectiveness Team for collation and analysis using Microsoft TM Excel. **100** questionnaires were distributed and **97** were returned giving a response rate of **97.0%**. Where possible the results from 2010 were compared against those from 2005.

#### Results

- **84.5%** (79.4% in 2005) of parents/carers rated their level of understanding of their child's epilepsy as "excellent" or "good".
- Of the **43** parents/carers whose child had been diagnosed with epilepsy in the preceding 3 years, **30** (69.8%) had received an information pack.
- **80.4%** (55.9%) of parents/carers had received information about epilepsy from the ESN.
- A number of methods were used by parents/carers to contact the ESN, **62.9%** (60.2%) had used the ESN's office telephone number, **52.6%** (30.8%) has used her mobile number and **38.1%** (14.7%) had used email.
- **95.9%** (83.8%) of parents/carers felt able to contact the ESN for advice. There were two comments that indicated that difficulties had been encountered by parents/carers when the ESN had been on annual leave or out of the office.
- **93.8%** of parents/carers felt supported to manage their child's epilepsy, **95.9%** (73.6%) felt they were given adequate information by the ESN about their child's epilepsy and **96.9%** (72.1%) felt that the ESN gave appropriate advice.
- Of the **57** families who had a child with a learning disability, **44** (77.2%) felt the service met their child's needs.
- **30** (30.9%) parents/carers were aware of the Quarriers Epilepsy Support Group meetings but only **three** (10%) had attended. Of the **65** who originally weren't aware of the meetings, **41** (63.1%) expressed an interest in attending meetings.
- Parents/carers gave a number of very positive comments about the service.



## **Conclusion**

This audit has been key in demonstrating the effectiveness of Grampian's ESN Service. Further improvements can and will be made in line with current research and best practice guidance whilst taking into account the views of parents/carers. Time has been a huge barrier to the development of the ESN Service. However the service has appointed an additional 0.5 wte through the National Delivery Plan. It is hoped that the audit will be repeated in due course to demonstrate the additional benefit to service delivery.

## **Action Plan**

- Dissemination of results, June 2011.
- Better cover of working week and during periods of annual and study leave, May 2011.
- Feedback parental views on Quarriers Support Group advertising, May 2011.
- Endeavour to telephone or home visit every child who is newly diagnosed with epilepsy, as near to time of diagnosis as possible, May 2012.
- Discuss mechanisms for supporting children with epilepsy and learning disability educationally with Consultant Psychiatrist in Learning Disability and Neuropsychologist, May 2012.
- Review and re-audit, January 2014.

**Jo Campbell**

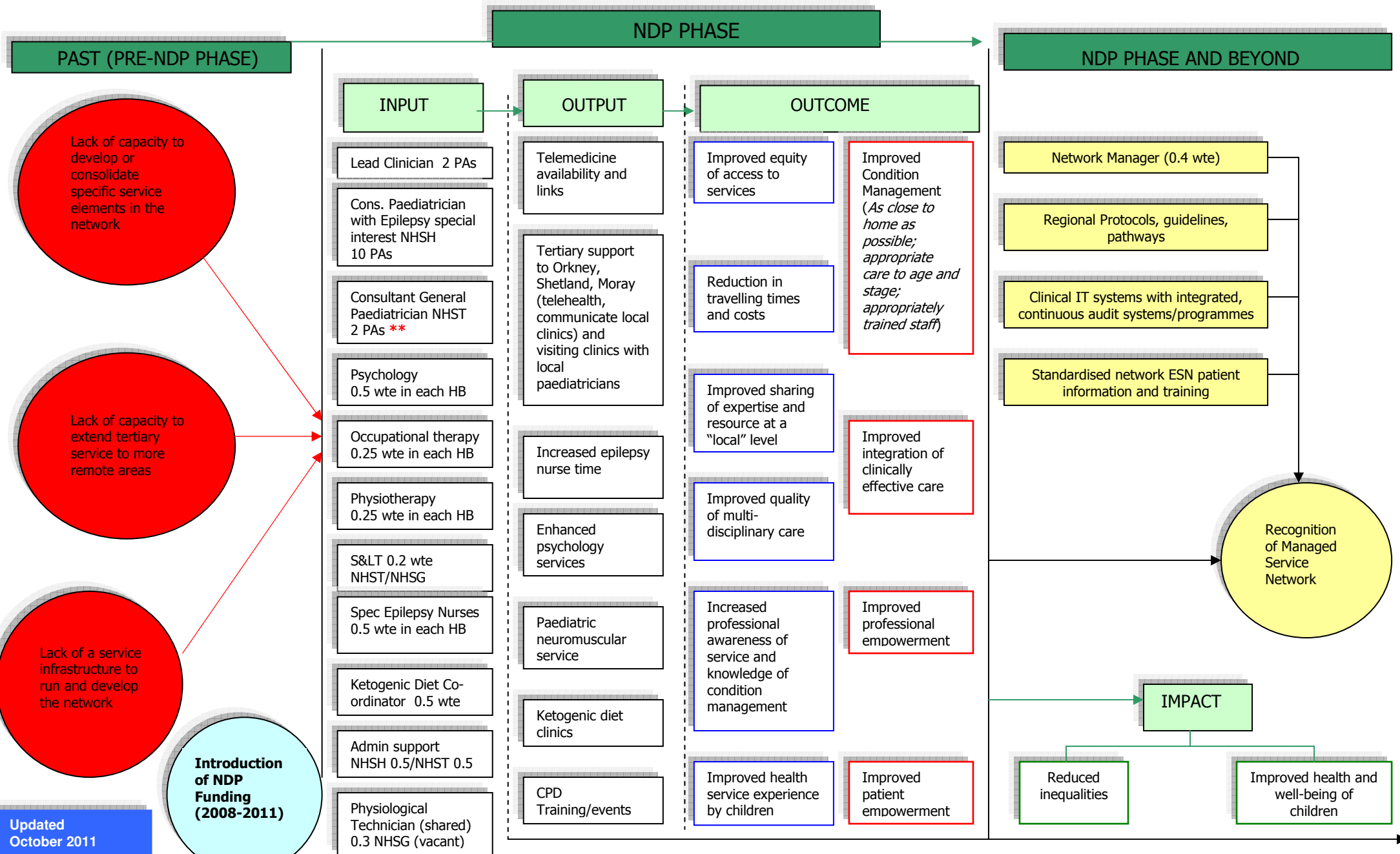
## **11. Looking Ahead**

Sincere thanks go to our team of highly motivated, hard-working staff who are making a big difference to standards of care for patients with a neurological condition across the North of Scotland. Recognition and thanks also go to the team for their contributions to our first network report. We will continue to build on the excellent collaborative work carried out to date and look forward to furthering the progress of the network for the benefit of our patients in 2012.

Network priorities for the coming year will be to:

- Increase epilepsy clinics in Elgin from quarterly to monthly
- Further develop network care pathways
- Develop NeSCANN web pages and patient information
- Continue to build on the work already completed on the network education framework
- Collaborate with NSD to ensure the Clinical Audit System meets the needs of the network
- Complete the education and training standards work to document the standardised training and information delivered by the Epilepsy Specialist Nurses.

# Appendix 1 - North Scotland Child & Adolescent Neurology Network (NeSCANN) – the Logic Model



Updated October 2011

\*\* To back-fill tertiary service input to Orkney/Shetland and also to neuromuscular service and intrathecal baclofen service across the Region

**Outcome and Impact Key** — Short-term outcome — Intermediate outcome — Long-term outcome (impact)

## Appendix 2 - North Scotland Child & Adolescent Neurology network - staff involved in delivery of NeSCANN

<i>NAME</i>	<i>POST</i>	<i>HRS</i>	<i>NDP</i>	
<b>ABERDEEN</b>				
Dr Ayaz Shah	Consultant Paediatrician	f/t		
Dr Elma Stephen	Consultant Paediatrician	f/t		
Dr Ann O'Hara	Associate Specialist	f/t		Also Clinical Lead for Scottish Paediatric Epilepsy Network
Carolyn Duncan	Child Health Network Manager	p/t	0.8	Also Network Manager for Gastroenterology and Respiratory NoS networks
Diane Honeyman	Medical Secretary	p/t		
Jo Campbell	Specialist Epilepsy Nurse	p/t		
Ena Cromar	Specialist Epilepsy Nurse	p/t	0.5	
Dr Bruce Downey	Neuro-psychologist	f/t	1.0	
Hilary Rennie	Dietitian	p/t		
Winnie Taylor	Lead Speech & Language Therapist	f/t	0.25	
Jo Thomas	Occupational Therapist	p/t	0.25	
Jane Tewnion	Physiotherapist Neuro-muscular Adviser	p/t	0.25	
Julie Ralston	Dietitian – Dr Gray's Elgin			
Physiological Technician	Post under discussion	f/t	1	Shared NDP funding with gastroenterology and respiratory networks
<b>DUNDEE</b>				
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist	f/t	2 PAs	Clinical Lead
Dr Alice Jollands	Consultant Paediatric Neurologist	f/t		
Dr Linda Clerihew	Consultant Paediatrician	f/t	2 PAs	
Sheila Kerr	Medical Secretary	p/t	0.5	
Karen Lawrence	Specialist Epilepsy Nurse	f/t		
Pauline McEachen	Specialist Epilepsy Nurse	p/t	0.5	
Aileen McCafferty	Neuro-psychologist	p/t	0.4	
Anne Keddie	Physiotherapist – Neuro-muscular	p/t	0.25	
Jo Armstrong	Physiotherapist – Intrathecal Baclofen	p/t	0.25	
Helen Grossi	Ketogenic Dietitian	f/t	0.5	
Heather Mitchell	Dietitian	p/t		
Zoe Whyte	Occupational Therapist	p/t	0.25	

<i>NAME</i>	<i>POST</i>	<i>HRS</i>	<i>NDP</i>	
<b>INVERNESS</b>				
Dr Alan Webb	Consultant Paediatrician with a Special Interest in Epilepsy	f/t	10 PAs	5 PAs for epilepsy service
Mandy Craib	Medical Secretary	f/t	0.5	
Dr Linda MacLellan	Consultant Paediatrician	f/t		
Dr Lesley Henderson	Consultant Paediatrician	f/t		
Jan Mackenzie	Specialist Epilepsy Nurse	f/t		
Kirsteen Mackintosh	Specialist Epilepsy Nurse	p/t	0.5	
Nikki Strachan	Dietitian			
Judy Shalcross	Dietitian - Wick			
Dr Tracy McGlynn	Psychologist	p/t	0.5	
Dr Rachel Smith	Psychologist	p/t	0.5	
<b>SHETLAND</b>				
Dr Susan Bowie	GP with a Special Interest			Based at Hillswick Health Centre
<b>ORKNEY</b>				
Catriona McCallum	Dietitian			



### Appendix 3 – North-east Scotland Child & Adolescent Neurology Network (NeSCANN) Work Plan 2011-2013

Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at December 2011
Formalise a Paediatric Neurology Steering Group	Identify membership across all North of Scotland Health Boards and ensure regional priorities for the network	<ul style="list-style-type: none"> <li>Develop role and remit of group</li> <li>Agree schedule of meetings</li> <li>Agree upon annual work plan</li> <li>Develop a performance monitoring framework to monitor the work plan</li> </ul>	2011	M Kirkpatrick C Duncan	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	<ul style="list-style-type: none"> <li>Liaise with local Health Board professionals to identify and address gaps in local policies</li> <li>Agree upon an implementation strategy, initially at the Child Health Clinical Planning Group level</li> </ul>	2011-2013	A Jollands A Shah M Kirkpatrick C Duncan	NHS Grampian and NHS Highland work to existing policies. Discussion ongoing with a policy in Tayside.
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	<ul style="list-style-type: none"> <li>Build on Ninewells telemedicine evaluation carried out in 2010 and carry out evaluation of clinical VC consultations</li> <li>Continue review of functioning of existing infrastructure and of gaps in current service</li> </ul>	2011-12	A Jollands C Duncan	
Map, develop and agree care pathways	Develop North region care pathways to ensure consistency across the network, enhancing links to national/other regional networks	<ul style="list-style-type: none"> <li>Identify existing care pathways and any gaps</li> <li>Link with national/regional groups to inform existing or new network protocols, standards and referral pathways</li> <li>Agree upon neurology care pathways for western Grampian area</li> </ul>	2011-12	A Jollands H Grossi J Campbell J Armstrong	Work ongoing between NHS Grampian and NHS Highland with arrangements for Moray epilepsy patients
Develop information for patients	Enhance patient/families' knowledge of service and of disease information	<ul style="list-style-type: none"> <li>Develop patient information and involvement leaflets</li> <li>Investigate Web possibilities to develop network website</li> </ul>	2011-13	A Jollands H Grossi J Campbell J Armstrong	
Continue to develop education framework	Scope current training provided, training needs of network staff and develop a planned curriculum of Continuing Professional Development	<ul style="list-style-type: none"> <li>Complete Training Needs survey</li> <li>Identify service and staff needs</li> <li>Map educational opportunities – local/regional/national</li> </ul>	2011-12	A Jollands C Duncan J Campbell E Cromar	Training needs survey completed autumn 2011. Regular training/education opportunities bulletins distributed regionally

Objectives	Outcome	Tasks	Time-scales	Lead Professionals	Progress at December 2011
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	<ul style="list-style-type: none"> <li>Gain agreement at NoSPG to develop and to provide ongoing funding</li> <li>Further discussions with NSD in order to tailor the system to meet service need</li> </ul>	2011-13	M Kirkpatrick A Jollands C Duncan	Discussions have been held with NSD and Clinical Audit System providers in order to progress adoption of this national IT system for NoSPG child health networks
Develop a universal standard of training & education delivered by Epilepsy Nurses across the region	Review and standardise epilepsy training packages and protocols for primary care and other care professionals involved in children's epilepsy	<ul style="list-style-type: none"> <li>Collate and review resources delivered by children's epilepsy nurses.</li> <li>Develop CPD currently delivered to include working with difficult families, children with behavioural difficulties, transition, VNS, ketogenic diet support, drugs information &amp; prescribing</li> <li>Develop standard protocols and guidelines e.g. emergency medication, seizure first aid, training for parents/carers/Education, teenage services and transitional care</li> </ul>	2011-2013	A Jollands J Campbell J Mackenzie K Lawrence	Group set up and a large amount of work undertaken to standardise training and information packages given to patients and families, carers and staff. Standards document almost complete.
Audit clinical care	Measure performance indicators in children's epilepsy care and review parents' and carers' experiences of service provided	<ul style="list-style-type: none"> <li>Participation in and collation of data for the Epilepsy 12 national audit</li> </ul>	Sept 2012	M Kirkpatrick	Large amount of work carried out by staff in 3 main centres to collate and submit data to the audit team. Once findings published in 2012, action plan will need to be put together in each unit/area.

#### 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