

# *NeSCANN*

*North of Scotland Child and  
Adolescent Neurology Network*

## **Annual Report 2015-16**



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## 1. Introduction

Welcome to the fifth annual report of the North Scotland Child and Adolescent Neurology Network (NeSCANN), which is the twelfth year the network has been in operation. The network was formalised following the injection of Scottish Government National Delivery Plan funding for Specialist Children's Services from 2008-2011. If you wish to view previous network annual reports, these can be accessed on the North of Scotland Planning Group website at <http://www.nospg.nhsscotland.com/index.php/child-health-camhs/nescann>

It has been a very busy year for our network multi-disciplinary staff delivering neurology and epilepsy services across the North of Scotland. The main aims of the network continue to be to provide patients and families with patient-centred, safe, effective, efficient, equitable and timely care across 5 North Health Boards.

## 2. Network Governance

Multi-disciplinary teams of dedicated, very experienced clinicians are committed to ensuring the sustainability of the network and to delivering the best quality of care as close to patients' homes as possible.

Dr Martin Kirkpatrick (Clinical Lead) and Carolyn Duncan (Network Manager) continue to support and lead the network across the region in collaboration with local Health Board clinician colleagues and managers. The network reports to the North of Scotland Planning Group (NoSPG).

We are very proud of the excellent team working and good communication carried out by our network's multi-disciplinary teams across the region. Staff continually review the models of care to make improvements to services provided across the wide geographical area that is the North of Scotland. Patient safety is at the heart of all that we do and network staff continue to work hard to drive standards up in the way care is delivered to our children and young people with a neurological condition.

### 2.1 Network Links

#### Scottish Paediatric Epilepsy Network (SPEN)

There are continued strong links with SPEN. Members of NeSCANN are involved in the SPEN Advisory Board and many of the sub-groups. Several network staff attended the SPEN Members' Day in Stirling in November as well as other interest groups such as educational sessions, roadshows and family days. Carsten Mandt took over as Programme Manager at SPEN in April and he hopes to be able to attend 2016 NeSCANN steering group meetings to keep our network up-to-date with what is happening within epilepsy across Scotland and nationally.

#### Scottish Muscle Network

There continues to be strong links with the Scottish Muscle Network, with network clinicians being closely involved in developments and service improvement updates. Dr Ann O'Hara has been heavily involved in both networks for a numbers of years and will be missed enormously when she retires in 2016. It is anticipated that clinicians in the north will continue to take an active role in the steering group and special interest groups in both networks in future. Carsten Mandt is also Programme Manager of this national network.

## **Scottish Paediatric Epilepsy Surgery MDT**

Network staff attended several meetings during the year of the Scottish Multi-Disciplinary Team Meeting on behalf of network patients who are being discussed for potential surgery to improve their epilepsy in Edinburgh. Please see an interesting patient story in section 3.9 on page 9, written by a network patient who has gone through the pathway and received successful epilepsy surgery in Edinburgh.

### **3. Service Updates**

#### **3.1 Staffing**

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

Staffing pressures due to vacancies or a lack of capacity continue to be present across the network. Network clinicians from Tayside assisted in RACH delivering clinics and support during the summer when there was a gap in medical staffing following the resignation of Dr Ayaz Shah in June 2015 and prior to a Consultant post being recruited to.

In addition Dr Alan Forster, Consultant Neurophysiologist in ARI also retired in June resulting in an increased workload for Consultant colleagues with regards reporting of paediatric EEGs. This was all in an environment where numbers of patients with a neurological condition are increasing year on year. On a positive note in RACH, the management team agreed increased epilepsy nursing hours in order to meet families' needs and Ena Cromar, Epilepsy Specialist Nurse, increased her hours of work to 30 from May.

We were delighted to welcome back to RACH Dr Vipin Tyagi, as Consultant Paediatrician with a special interest in neurology in the summer following a period in England. Dr Tyagi will work in both Aberdeen and Elgin and will have responsibility for neurology in RACH and neurology and neurodevelopmental patients as well as general paediatrics at Dr Gray's Elgin.

Dr Ann O'Hara has been working as a part-time Locum in RACH following her official retirement date in early 2015. Discussions have been ongoing with the child health management team in Grampian to advertise a new Consultant post with a special interest in neurology which is anticipated will be recruited to in summer 2016.

We said goodbye to Faye Chappell, Regional Paediatric Neuromuscular Physiotherapist (13 hrs), who left the region in August. There has been a gap in service since her departure but the post will be recruited to in late spring 2016 to include some additional responsibilities with regards a point of contact for neuromuscular patients (please read more in section 3.5.3 on page 8).

#### **3.2 NeSCANN Steering Group**

Four network steering group meetings took place during the year. Together with network business, clinical guidelines, services issues, network and national reports and a number of pathways and standards were discussed or worked on. Some examples of topics discussed include -

- Continuing Seizures pathway - audit and patient watchers' lists completion
- Moray Epilepsy service delivery
- Metabolic screening for children with developmental delay

- Regional ketogenic diet service and referrals
- North of Scotland neurophysiology services
- Regional neuromuscular physiotherapy
- MHRA advice on the use of sodium valproate in girls
- Use of oxygen in hospital when patients admitted with seizures
- IT – clinicians’ access to Health Board systems and issues with signing clinical letters across boundaries
- EEG data reporting and remote access to EEGs
- The long standing issue of the lack of a regional database for network patients.

### 3.3 Work Plan

Objectives in the 2015-16 collaborative work plan were progressed during the year, please see *Appendix 2*. The work plan is continually performance managed by a RAG status system.

- The network continually updated **network structure documents** during the year, i.e. Terms of Reference of the group, risk register and work plan. Network staff also had input to the North of Scotland Planning Group ‘Framework for Tertiary Paediatric Services’ document, which continues to evolve as a regional document and which includes subjects such as, clinical practice, job planning, succession planning, education, governance, data and leadership.
- **Review of secondary and tertiary clinics** within the network has taken place following new clinical appointments in Aberdeen and Dundee.
- A lot of collaborative work was also undertaken to agree a **network Patient Information leaflet** for families, explaining how the network functions with regards in- and out-patient services. Following a pilot and evaluation the leaflet was published during the year and can be accessed on the NoSPG web pages at <http://goo.gl/poJQY3>
- The video-conference (VC) use in an **out-patient review appointment guide** for parents and families was published during the year. It can either be printed off or parents can be directed to the network page on the North of Scotland Planning Group website <http://www.nospog.nhsscotland.com/child-health-camhs/nescann/>
- A Short Life Working Group will be convened to review **care pathways** and guidelines that are currently on local Health Board Intranet sites and to decide on what should be included for the benefit of professionals initially. There is also work going on in Grampian to develop their Clinical Guidance Intranet which network staff will develop pages for neurology and neurodisability.
- **Data** - NeSCANN clinicians continue to input in a limited way to the SPEN version of the Clinical Audit System. The lack of an appropriate database for NoS network patients is a long standing issue. Collection of data has been a recurring theme within all child health networks, with no one IT system or database available in the North that will allow collection of data on network patients. In addition there have been cross boundary access issues to Health Boards’ clinical systems allowing clinicians access to up-to-date data or test results. These issues have been raised with the North of Scotland e-Health Leads’ group and it is hoped that in collaboration with this group that solutions can be found to most of the access issues.
- **Research & Audit** - Network staff have been able to recruit patients and families for participation in a number of audits during the year, e.g. Epilepsy 12, GACE, Sanad 2.

### **3.4 Highland-Moray Epilepsy Service**

Epilepsy clinics continue to be delivered every 2 months at Dr Gray's Elgin by Dr Alan Webb (Consultant with a special interest, NHS Highland) with valued input from the NHS Highland Specialist Epilepsy Nurses and Dr Shelagh Parkinson in her role as local paediatrician with an interest in neurodisability at Dr Gray's. 27 patients are currently on treatment with 29 epilepsy patients being followed up regularly. Two patients transitioned to adult services during the year. The majority of neurophysiology and neuroradiological investigations have been organised by Dr Webb and carried out timeously at Raigmore Hospital in Inverness which is of great benefit to Moray patients.

In accordance with our network planning to transfer care on a phased basis to Dr Webb, increasing numbers of epilepsy with additional needs patients have been seen in Dr Webb's Elgin epilepsy clinic during the year. Moray patients were given the option to continue to be cared for by Grampian clinicians whom they have known and been cared for often for several years however several patients and families have opted to continue to be seen or treated by NHS Grampian clinicians rather than see Dr Webb.

Epilepsy training for local authority education staff is now being delivered in Moray by the NHS Highland Epilepsy Specialist Nurses. During the year training was provided in Moray in 2 secondary schools, 5 primary schools and 2 nurseries by Highland ESNs.

### **3.5 Epilepsy Specialist Nurse Group**

Very positive collaborative work and good discussion is carried out by the group. It was agreed that a generic ESN training pack was developed to be used by each centre's ESNs and work continues on this in each of the main centres.

The network Epilepsy Specialist Nurse folder containing a large number of standard network templates, guidelines and forms was reviewed during the year and amendments and additions made by the group to ensure consistency and standardisation where appropriate across the region.

### **3.6 Allied Health Professionals**

#### **3.6.1 Intrathecal Baclofen (ITB) Service Update**

##### **Clinics & Service Development**

We continue to hold 2-3 Multi-Disciplinary Team (MDT) tone management clinics per year in Dundee for children in Tayside with complex tone management problems; this was held jointly with Dr Paul Eunson (Edinburgh Sick Children's Hospital) in September 2015. We have a similar clinic planned in Grampian, which will be our first in this region. We have had a further 2 successful pump implants over the past year, one child from Tayside and one from Highland. There are 2 Tayside children planned for trial over the next couple of months. I am still planning to develop an 'annual review' for children who have ITB pumps and am working alongside other physiotherapists involved in ITB services to establish the best outcome measures and goal planning procedures to use for this.

## **Scottish ITB Seminar**

Dr Martin Kirkpatrick and I have now successfully planned two Scottish ITB Seminars in May and November 2015 entitled 'Sharing Practice in Intrathecal Baclofen Management', with a third being planned for April 2016. MDT representatives working in paediatric and adult ITB services across Scotland have attended and it is proving to be a well regarded forum for networking and sharing practice in ITB management. We are currently taking forward pieces of work in 'Emergency care pathways' and 'Outcome Measures' with the group, whilst the seminars are becoming a good link for discussing standards of care in ITB services across the country. We plan to continue to organise these seminars on a twice yearly basis.

## **Non-Medical Prescribing**

I am pleased to report that I passed my non-medical Prescribing Module last year from the University of Dundee and am now both an Independent and Supplementary Physiotherapy Prescriber. I continue to establish my role within prescribing and tone management and I am looking forward to where this will take me.

**Jo Clough, Physiotherapist**

### **3.6.2 Ketogenic Diet Service update**

The Ketogenic Diet Service continues to grow throughout the North of Scotland with numbers of patients being referred for the Ketogenic treatment continuing to rise.

Joint clinics continue to be held in Ninewells Hospital, RACH and Raigmore Hospital and Balfour Hospital, Kirkwall with Dr Martin Kirkpatrick, Dr Alice Jollands, Dr Linda MacLellan and Dr Philip Brink together with the Epilepsy Specialist Nurses and Paediatric Dietitians in each area.

Helen Grossi has been involved with providing local teaching sessions throughout the region to health (including Pharmacists across Tayside), education and social care staff to increase awareness and knowledge of the Ketogenic Diet.

Helen also presented and chaired sessions at the Ketoconference, held in London in April 2015 and is a member of the National Keto Advisory Group. She also leads the Scottish Ketogenic Diet Group where work is being carried out to streamline documentation and treatment used throughout the whole of Scotland for the Ketogenic Diet. This also provides a forum for networking and collaborative working.

The Ketogenic Diet Service held a Keto Family Day at the AK Bell Library in Perth in August. This day gave families of children on the Ketogenic diet across Scotland a chance to meet up, to discuss their experiences and to network. This was also an opportunity for education and learning and the Scottish Ketogenic Dietitians spoke about some of the practicalities of the diet. We also had Emma Williams (CEO of 'Matthew's Friends', a charity which supports families on the Ketogenic Diet) who spoke of her experience with the diet and Neil Palliser-Bosomworth (who is a chef who works with Matthew's Friend's) demonstrating recipes and giving the families a chance to try different foods and recipes and giving them the opportunity to ask questions. This day had very positive feedback from the families who attended.

There has also been significant work carried out this year, looking at suitable medications for children on the Ketogenic Diet. Medicines which contain high levels

of carbohydrate are unsuitable and can cause difficulties in maintaining ketosis for those on the diet.

Tracy Cameron, RD and Iain Hewitt (Specialist Pharmacist, Women and Child Health, Ninewells Hospital) and Helen Grossi have developed an information sheet for use by medical and nursing staff on the wards, by GPs and any other areas such as Respite units, where the children may have medication prescribed. This leaflet informs the staff on which common medications are suitable for children on the Ketogenic Diet. So far, this has been distributed to the wards in Ninewells Hospital and the GPs of children on the diet. The plan is that this will be distributed to other areas of NeSCANN after consultation with appropriate staff in these areas.

**Helen Grossi & Tracy Cameron**

### **3.6.3 Paediatric Neuromuscular Update**

There had been many regional discussions about a long-standing issue regarding the provision of a regional service for neuromuscular patients (including adults and paediatrics). However following NeSCANN discussions and conversations with NoSPG managers, it was agreed that a solution for paediatrics could be sought within current resources. There has been no additional funding made available for a permanent Neuromuscular Care Advisor role (Scottish Government provided temporary funding for 2 years) in the North and it was agreed by the network that the vacant Regional Neuromuscular Physiotherapist post (13 hrs) job description should be reviewed. A Short Life Working Group was convened to revise this post's job description in order to combine some elements of the previous regional Care Advisor role. A revised job description for the Regional Neuromuscular Physiotherapist was agreed – the post will now act as a point of contact for advice and support for paediatric neuromuscular patients and families and will continue to be the link with the national Scottish Muscle Network. The post was advertised in March 2016 and it is hoped it will be recruited to by late Spring/early summer.

### **3.7 Neuropsychology Research – PIE Study**

Members of the neurology team at RACH have been involved in a national RCT (Randomised Control Trial) research study evaluating the efficacy of a psychosocial group intervention for adolescents with epilepsy. Termed the PIE (Psychosocial Intervention in Epilepsy) study, the project has a number of key aims directed at,

- (i) improving adolescents' knowledge about their condition,
- (ii) facilitating self-management and readiness for transition to adult services, and
- (iii) improving psychological wellbeing, coping and quality of life.

Dr Bruce Downey (Clinical Paediatric Neuropsychologist) is the local Principal Investigator for the study and to date both Bruce and Mrs Jo Campbell (Epilepsy Specialist Nurse) have successfully completed the intervention arm of the project; which consisted of running 2 x 6 week group interventions with those who enrolled into the study. These sessions were all held at RACH.

Feedback received from both the adolescents and the parents that took part in the study has been overwhelmingly positive - with one child asking on their feedback form, 'Can I come to the next group?' Preliminary results from the study are currently being analysed by the Chief Investigator's team based at the Royal Hospital for Children, Glasgow; with dissemination of this pending.

**Dr Bruce Downey, Neuropsychologist**

### 3.8 Patient Stories

#### **Kindly provided by a young person from Skye who has epilepsy –**

'I firstly want to thank everyone who was involved in my surgery and with everything that led up to it. You are a great team and you really know how to make sure that we know everything and that we feel comfortable with what's going to happen. Before the surgery I went to go and see the doctors at Dundee and Edinburgh a few times to discuss what was going to happen and settle all the dates. They were very flexible and considering around the dates due to the fact that I had stuff on earlier in the year.

Also as well as that Jenny came to see us while we were camping in the summer to go over everything again and answer all of our questions that we had. I had a few MRI scans that were a bit scary but the team are great and they play music and a movie that you want to watch or listen to. All the teams that I went to see are so nice and understanding.

The day before and on the day of my surgery I had all the doctors come to see me again and check up on me one last time and to make sure again that everything was alright and that I was coping okay with what was going to happen. The nurses that were in the ward are really nice and know how to make you smile when you are feeling low. They are always there to talk to if you don't feel well or just need support.

Another big thank you to Dr Sokol and Dr Kirkpatrick for all their support. Also a big thanks to Jenny who came to see me a few times and also phoned me before and after the surgery to see how I was doing. The lead up to the surgery was way more relaxed than I thought it was going to be. This was due to all the amazing teams that were involved in making everything so calm and chilled. There is nothing in particular that I would say that was bad or you should change. From my experience everything was great. All the teams knew exactly what they needed to do to make the situation 100% more relaxed than I originally thought it was going to be.'

#### **Our experience of the Ketogenic Diet by the Family of F**

F was at the stage where he was constantly having seizure after seizure day and night and our family life was quite difficult. However, it took only 3-4 weeks from the start (of the Ketogenic Diet) to change our lives completely. F has been seizure free since then and that was 7 months ago.

At first, it's a daunting task I didn't think I would be able to manage, but my Dietitian did say I would be an expert in no time – I didn't think so. However, she was correct.

It's difficult at first, especially if you're not a cook, like me. But, after a few weeks it's like riding a bike – you wonder what you were stressing about. The EKM Calculator is a godsend though it takes only 5 minutes to get the values for a meal if F decides to change his mind about what he wants to eat.

F has seen the benefits of his 'magic' diet as well. At first, because of how he felt, with all the seizure activity, he wasn't happy. After a couple of weeks of seeing the benefits of being able to play and concentrate the way he used to, he never wants to stray/cheat on his diet. He is a much happier boy – the way he used to be. There is still the odd occasion where he gets an upset tummy, but F just shrugs it off and says it doesn't last long anyway.

## **Improved Patient Care due to Cross-boundary Collaboration**

A 6 year old boy was referred to the epilepsy service in Moray by his GP following a history of losing concentration, eyes glazing over and periods of being unresponsive. These episodes had been noticed over a few months and had become more frequent.

The child was seen at the epilepsy clinic in Elgin by Dr Webb and the Epilepsy Specialist Nurse within 4 weeks of the referral being received. A history of events was taken and having an EEG was discussed with the family and arranged to take place at Raigmore in Inverness. The parents were able to attend at short notice for their child's EEG and as a result were offered a cancellation 3 days later.

Following the EEG, medication of Sodium Valproate was commenced as the history indicated generalised epilepsy. During Sodium Valproate titration and regular telephone review conversations, it was found that the use of Sodium Valproate was proving to be unsuccessful for the patient. Following further history taking and communication with the family with regards ongoing seizures, the child's presentation was indicating towards a focal type epilepsy. The formal EEG report was not suggestive of childhood absence epilepsy and it was suggested MRI imaging would be appropriate. An MRI scan was arranged and the child was prepared for the scan together with a Play Specialist at Raigmore Hospital. This meant that the MRI scan was able to be successfully carried out without the patient's need for a general anaesthetic.

Following the results of the MRI scan, it was agreed that the medication the child was taking should be changed to carbamazepine. This has been successful and the child is now seizure free. This clearly demonstrates the benefits of quality care being delivered in a timely and effective way and that cross boundary care undertaken between Moray and Highland works well for a number of patients.

**Kelly McBeath & Kirsteen Mackintosh, Epilepsy Specialist Nurses**

### **Mary's Journey on our NESCANN seizure care pathway**

In 2014 NESCANN ratified a 'Continuing Seizure Care Pathway' to ensure all children living in the North had appropriate, timely and good quality care including access to the national surgical pathway when their epilepsy was difficult.

\*Mary's story illustrates how this works and the importance of team working to ensure that children like her get the best possible care.

Mary lives approximately 30 minutes drive from the Royal Aberdeen Children's Hospital (RACH). She has significant learning difficulties and a refractory seizure disorder which manifested as troublesome drops and prolonged episodes of non-convulsive status epilepticus. Both were proving problematic with the drops confining her to a wheelchair so as to prevent unnecessary injuries.

Her initial evaluation was through the local RACH paediatric team including the invaluable support of the Epilepsy Specialist Nurses (ESN). She was discussed at the monthly peer review meetings at RACH and subsequently reviewed at the visiting tertiary level clinic at RACH by one of the tertiary level paediatric neurologists.

Most of her special investigations were co-ordinated by the local team at RACH, including brain scans, blood tests and routine EEGs. As she was not responding to standard anti-epileptic drug therapies she was referred to our Ketogenic Diet Service.

A trial of ketogenic diet therapy was achieved together with the local dietetic and regional ketogenic diet service, local ESN and paediatric services. Sadly Mary did not respond to this intervention.

Arrangements were made for her to go to Tayside Children's Hospital at Ninewells for specialised video telemetry EEG recordings over a period of 4 days. Accommodation for her parents in the Ronald McDonald Suite adjacent to the paediatric unit was provided as this was a very long way from home.

Her clinical history and results of all her specialised investigations were subsequently presented at the national Epilepsy surgery multi-disciplinary meeting. Her local team were able to join the discussions using video-conferencing. This was really helpful as they knew her and her family best and added a more personal dimension to her story.

Mary and her family then visited the Royal Hospital for Sick Children in Edinburgh before planned surgery for her epileptic drops. She tolerated her surgery without complication and almost immediately her family were reporting a cessation of her drops. Mary was also reported to be much brighter with a dramatically improved quality of life – she wasn't confined to her wheelchair anymore!

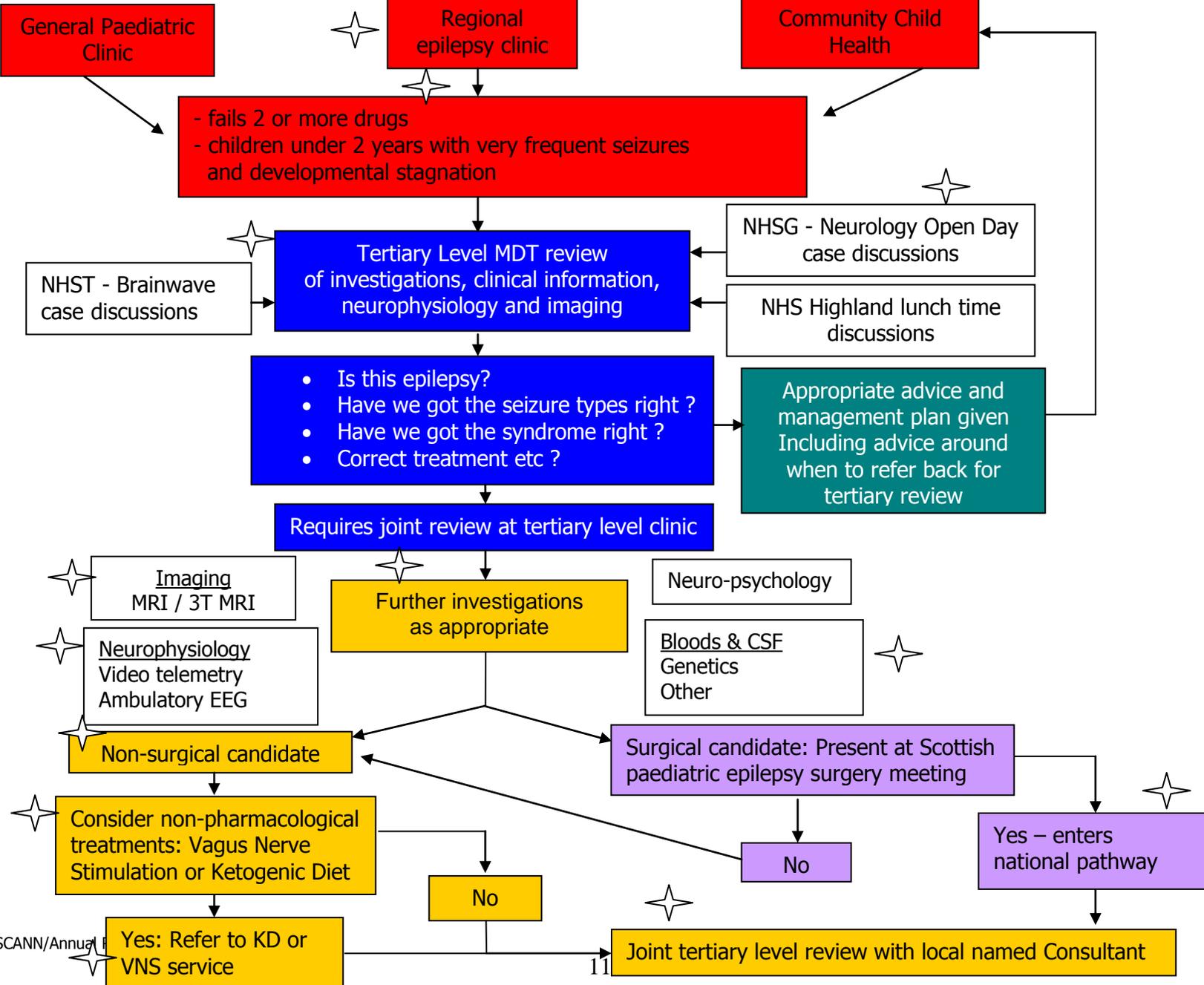
The next step will be to address her ongoing difficulties with episodes of non-convulsive status. Vagal nerve stimulation was considered a suitable modality to explore. Teamwork has and will continue to be key but with well established pathways and excellent team working we hope to continue to optimise her care and quality of life.

(\* Mary's name has been changed for the purpose of this patient story to protect her identity).



The stars highlighted on the network care pathway below indicate how the pathway worked with regards \*Mary's care.

**Continuing Epileptic Seizures**  
**NeSCANN Care Pathway (Incorporating SPEN care pathway)** January 2014



## 4. Training & Education

The network is committed to ensuring staff are well trained and highly skilled and there were a number of educational opportunities available to professionals across the network during the year where key teaching and learning took place.

In addition monthly multi-disciplinary meetings take place in the 3 main centres i.e.

- Brainwave (Ninewells) – now available across the region by VC
- Neurology Open Day (RACH)
- Raigmore, Inverness lunchtime sessions alongside the visiting Consultant Neurologist clinics.

These provide regular teaching and educational forums for learning, e.g. discussions on complex cases, developments, audit, brain imaging and neurophysiological investigations.

A number of meetings have been attended by network clinicians, e.g.

- BPNA annual conference
- Scottish Paediatric Neurology Group
- SPEN Members' and Research days
- SPEN special interest group meetings
- RCPCH annual conference

Our network clinicians have also been leading the distance learning PET programme through the British Paediatric Neurology Association both nationally and internationally.

### 4.1 NOD - Neurology Open Day Meetings in Aberdeen

The first meeting of this virtual clinic took place on 25<sup>th</sup> August 2005 with 11 cases being discussed. The name Neurology Open Day was chosen. This was to encompass the aim of this meeting being open to all colleagues to discuss any case with the neurology team as well as ensuring clinical governance and peer review (before we knew what these terms were) within our Neurology Network. We also hoped that if children's cases were discussed in detail with colleagues in radiology and neurophysiology that we could enhance appropriate ongoing management and perhaps save some families additional clinic appointments. It just so happened that the first two children discussed had movement disorders of their heads and the term NOD day has stuck. (It can be changed.)

NOD has run on a regular basis since and has evolved over time. We review scans, EEGs, have case discussions and we have reinstated CPD sessions. Clinical care has definitely benefitted from the strengthening of good relationships with colleagues in Psychology, Neuroimaging and Neurophysiology and we have all learned from each other. Clinical decisions have been changed to patient benefit as a result. We have had input from colleagues from acute and community paediatrics, surgery, neurosurgery, CAMHS, genetics, AHPs. It has proved to be an invaluable resource for continuing medical education at all levels.

I think it has been very useful to us as a team and to families so that we all know about complicated children if problems arise when their "usual doctor" is on leave or working elsewhere.

We have also been ahead of the game in the network with a well established format used, for example, following national guidelines on epilepsy management for children and young people with a refractory epilepsy.

Sometimes we tried to do too much and a decision was made to stop having a business meeting during the day some years ago. Thank you too to colleagues who ran meetings in my absence.

In 2015-2016 we have had 8 meetings with 201 cases discussed. They have ranged from 6 in the first year to maximum of 10 depending on annual BPNA conference, Christmas and staff availability. Some discussions may simply be brief updates while others may be quite lengthy. We have made more use of videoconferencing with good effect.

On a personal note I am delighted that NOD will continue on as I feel it is an integral part of the care that families in the North East are offered by NeSCANN. It will be in very sound hands with Dr Stephen who will continue to develop these invaluable sessions. It may also come as a shock to you all to know that I have initiated the process of conversion from paper to e-documentation. Thank you to all my colleagues involved in making NOD a success, for your support and tolerating my attempts at time management. Who am I going to chivvy on now on the 4<sup>th</sup> Thursday of the month?!

**Dr Ann O'Hara, Associate Specialist**

## 4.2 Network Study Event – September 2015, Inverness

A very interesting and informative educational network study afternoon took place in Raigmore on 15<sup>th</sup> September 2015 - we had 5 VC sites linking in from across the North of Scotland! Guest speakers included Dr Linda Clerihew, Consultant Paediatrician (Ninewells) and Clinical Lead of the Scottish Patient Safety Programme, who gave an interesting talk on their work and how it can influence the work of NeSCANN.

Dr Patrick Fox, Consultant Neurophysiologist (Raigmore), also gave a fascinating, interactive presentation and case study on nerve conduction tests carried out on a young patient. Dr Jollands presented her detailed work on the development of her pathway on the Investigation of Developmental Delay. Helen Grossi also provided us with an update on the regional ketogenic diet service.



## 4.3 PET1 and CHaT courses

This year, on behalf of the British Paediatric Neurology Association (BPNA), we hosted paediatric epilepsy training courses at the Suttie Centre in Aberdeen - PET1 (Paediatric Epilepsy Training), October 2015 - as well as Children's Headache, CHaT1- March 2015. Both courses were well attended by a range of professionals including trainee paediatricians, consultants, neurophysiology technicians and GPs. Very positive feedback was given with regard to the quality of the teaching with most attendees keen to promote these opportunities in their areas.

Trainee paediatricians particularly found the courses helpful towards meeting their curriculum competencies. Dr Elma Stephen, Dr Ann O'Hara and Jo Campbell

participated as faculty in the courses led by Dr Jollands (Course Director). A special mention is also made for the efforts of our highly efficient administrator Kathryn Reid, who undertook the organisational aspects of both courses locally along with Dr Stephen. In addition, Dr Stephen was privileged to participate in the South India launch of the International Paediatric Epilepsy Training 1 (iPET1) and 'Train the Trainers' course in Bangalore in March 2016, alongside Dr Kirkpatrick who is the Chair of the Education, Quality & Standards Committee of the British Paediatric Neurology Association.

**Dr Elma Stephen**

#### 4.4 International Paediatric Epilepsy Training (iPET)

A number of NeSCANN clinicians have been actively involved as trainers for PET (Paediatric Epilepsy Training) courses in the UK. These courses are run by the British Paediatric Neurology Association and now form part of some of the obligatory training for paediatricians involved in epilepsy care. These run over all of the UK including Scotland and more than 6,500 clinicians have been through a PET course in the UK over the last 10 years.

More recently our highly experienced north of Scotland clinicians, Dr Martin Kirkpatrick, Dr Alice Jollands and Dr Elma Stephen have contributed to the delivery of these courses overseas. PET courses have now been delivered in the Middle East Gulf States, Nepal, Burma, Sudan, South Africa and in many cities across India. This has allowed the further development of quality standards for all the courses, both in the UK and internationally. The experience gained from running the "train the trainer" elements of the PET courses is also of direct benefit to continuing the improvement of children's epilepsy education in Scotland and, in particular, the north. There are plans to more formally look at outcomes from the PET course to ensure their continuing role in raising quality of care for children with epilepsy.

Earlier in the year, Dr Kirkpatrick and Dr Stephen were also involved in the South India launch of establishing a PET training programme in Bangalore with a population catchment area of 400 million people - see newspaper article below. Dr Ann Agnes Mathew mentioned below was a trainee in Dundee 10 years ago.



Photograph caption: Training event in the city for the management of consciousness disease (seizures) participated in by Dr Ann Agnes Mathew, Dr Martin Kirkpatrick and others.

**Headline: Training for the management of consciousness disease (seizures)**

**Subhead line: Target to train more than 1000 paediatricians.**

Report:

Bangalore, Dr Anne Agnes Mathew of Rainbow Hospital gave a statement saying >1000 paediatricians in the state will be trained to manage consciousness disease (seizures disorder) affecting children. She spoke to the reporters after the inauguration of this training event by paediatric neurology foundation and British Paediatric Neurology Association.

In children epilepsy (Apasmara disease) is being increasingly recognised. In our country 1% of children reported to have seizures. There are also reports of febrile seizures in 5% of children. Urgent priority must be given to control this disease. Based on this background paediatric neurologists are being trained now.

In northern India over 6 months >500 doctors have been trained. Now in Southern India training has started. This inaugural part of the training is being held in Bangalore. Those who are trained will be certified by BPNA.

Participants in this event are Neurologist for NIMHANS Dr P S Bindu, Famous paediatric neurologists from England Dr Martin Kirkpatrick, Dr Ramesh Venkateshwaran from America, BPNA Director Philipa Rodie, Dr Mahesh Kamate from KEL Medical College Belgaum, Dr Velayudham Murugan

There is also a related report (Dr A A Mathew statement) -There is a severe shortage of paediatric neurologists in India. There are only 10 in the state and only one Belgaum. With such severe shortage of paediatric neurologists it has been a challenge managing this condition. In order to overcome this problem paediatricians are being trained in the management of this disease. There are different types in this condition and it is important to recognise different types, how to manage each of these. It is also important to differentiate which one of these conditions are worrying ones.

#### **4.5 Congratulations to our Grampian Epilepsy Specialist Nurses!**

**Jo Campbell** successfully gained her MSc in Advanced Nursing Practice in December culminating in a graduation ceremony held, by the Robert Gordon University, at the Music Hall in Aberdeen.



Aspects of the course included Research, Leading and Advancing Nursing Practice, Leadership and Professional Knowledge for nurse led practice. Additionally her work based project included a patient survey to ascertain parents' perspectives on the in an attempt to answer the question: Are monitoring systems effective for children with epilepsy during sleep? Jo was invited to and presented her findings at the Scottish Parliament and several local and national meetings.

**Ena Cromar**, Children's Epilepsy Specialist Nurse has been awarded a Certificate of Credit (60 credits) on the completion of The Care of People with Epilepsy course at Napier University. This consisted of 3 modules:-

1. Diagnosis and Management of Epilepsy. The area she covered in her essay was the management of Dravet syndrome. She looked at the pharmacological treatments and why particular antiepileptic medications are used; focusing on adjunctive medication.
2. Management of Psychosocial Issues in Long –Term Conditions. As children spend a significant amount of time at school She decided to write a report on the impact epilepsy has on learning, she concentrated on how epilepsy affects learning, cognition, attention and memory of children and young people.
3. Work based Learning. This module involved completing a portfolio with the aim of providing parents and carers with accurate, relevant and up to date written information on the Ketogenic Diet.

Since completing the work based learning module I have discussed with Helen Grossi the monitoring of children on the Ketogenic diet and we now plan to develop a database which will include a checklist and timetable to monitor children and young people on the Ketogenic diet.

## **5. Research & Audit**

### **5.1 GACE (Genetic & Autoimmune Childhood Epilepsy) Study**

This national Scottish study aims to study all children under 3 years of age who present with new onset epilepsy, looking at both the aetiology of their epilepsy and their outcome. Around one third of these children have seizures uncontrolled by medication and often associated with learning disability and behaviour problems.

This 3 year study will use a panel of some 80 different genes linked to childhood epilepsy and also look for possible auto-immune causes. Dr O'Hara, Dr Webb and Dr Kirkpatrick are the local leads for the study involving network patients in Grampian, Highland and Tayside. This will be a valuable study for a group of children who are often difficult to manage and difficult to get a correct diagnosis for.

### **5.2 SANAD2**

North of Scotland clinicians continue to be involved in this study with network patients. The study is comparing the effectiveness and cost-effectiveness of the anti-epileptic drugs and examines the quality of life in patients with newly diagnosed epilepsy.

### **5.3 Epilepsy 12**

Further work on the Epilepsy 12 action plans was completed at the start of the year. It was confirmed during the year that HQIP (Healthcare Quality Improvement Partnership - England) has agreed that there will be further development of Epilepsy 12 in future which is likely to be a five year programme. It will include a lot of work on Performance Indicators with data to be collected prospectively.

## **6. Key Challenges**

- IT issues continue to be challenging throughout the network although there have been some minor improvements. It is now possible to sign off electronic letters in a few north Boards however this is not possible across all 5 health boards. Even in those Boards where clinicians are able to sign letters off, they are often unable to make amendments to letters. This and other IT access issues across the region for paediatric networks have been collated and passed to the North of Scotland Planning Group for discussion and advice on possible solutions at the NoS e-Health Leads Group. There is still no regional database for network patients and again this continues to be discussed at NoSPG.
- The ability to collect data on network patients and the lack of a regional database continues. However there are improvements in remote access to patient data through Sci Store and Trakcare.
- Recruitment to the new Consultant post in Grampian with part-time responsibility for neurology will be progressed during the year. However it is acknowledged that this post will be difficult to recruit to given the lack of trained staff available nationally.

## **7. Looking Ahead**

A large piece of work will be progressed with SPEN and Epilepsy 12 during the coming year by network clinicians looking at national epilepsy key performance indicators that should be embedded into any future IT data systems. Data collection on epilepsy and neurology patients needs to be embedded into everyday practice therefore this will remain a major network priority in the coming year.

It has been a very busy year for all network clinicians. Our dedicated, committed staff continue to work over and above their working hours to ensure provision of the best quality of care to epilepsy and neurology patients across the north of Scotland.

We will continue to provide safe, effective, timely care and to drive up standards and to make service improvements by working on network care pathways and quality improvements to services. The network is committed to providing a skilled workforce and will continue to provide access to monthly regional learning and educational opportunities in future.

## **8. Network Thanks**

Network staff will have to bid a fond farewell to Dr Ann O'Hara, Associate Specialist in Paediatric Neurology, when she finally retires from RACH during the summer of 2016. Ann has been here since the beginning of the Network, and indeed long before. She almost singlehandedly held together the neurology service in Aberdeen at various times during a very difficult period from the time of the move of Dr Gaynor Cole away from Aberdeen in the mid 1990s until the establishment of the Network.

She supported and locally drove the formation of the Network and introduced what is probably a unique model of a combined virtual clinic/peer review clinic day that is now established throughout the network. She ran this tirelessly and efficiently pretty much every single month for the best part of 10 years and few probably appreciated the considerable and assiduous work that she put into this all of the time. The NOD (Neurology Open Day) has been, and will continue to be, an enormous contribution to the quality of care within the Network and is probably the prime example of what a high quality specialist tertiary network should be providing. She looked after the occasional moderately disorganised and over-committed neurologist, she ran the muscle clinic, she ran the Orkney and Shetland clinics and she probably ran up Munros too.

Above all, Ann is and always has been irrepressibly cheerful and enthusiastic, and one of the stalwarts of the RACH. Quite hard to think of a better colleague – all the best for your retirement Ann.

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

Network Management	POST	Comment
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist	Clinical Lead
Carolyn Duncan	Child Health Network Manager	Also Network Manager for Gastroenterology and Respiratory NoS networks

NAME	POST	
<b>ABERDEEN</b>		
Dr Vipin Tyagi	Consultant Paediatrician	Neurology/RACH & Dr Gray's, Elgin
Dr Elma Stephen	Consultant Paediatrician	
Dr Ann O'Hara	Associate Specialist/Locum	
Dr Ayaz Shah	Consultant Paediatrician	Resigned June 2015
Diane Honeyman	Medical Secretary	
Jo Campbell	Specialist Epilepsy Nurse	
Ena Cromar	Specialist Epilepsy Nurse	Part-time
Dr Bruce Downey	Neuro-Psychologist	
Helen Grossi	Ketogenic Diet Co-ordinator	0.5 wte
Hilary Rennie	Dietitian	
Winnie Taylor	Lead Speech & Language Therapist	
Jane Tewnton	Physiotherapist Neuromuscular adviser	9 hours
Julie Dobson	Dietitian – Dr Gray's Elgin	
Physiological Technician		0.3 wte funding (purchasing services)
<b>DUNDEE</b>		
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist	Also working in Grampian, Highland & Shetland
Dr Alice Jollands	Consultant Paediatric Neurologist	Also working in Grampian, Highland & Orkney
Dr Philip Brink	Locum Consultant Paediatric Neurologist	Also working in Grampian, Highland & Shetland
Dr Linda Clerihew	Consultant Paediatrician	
Sheila Kerr	Medical Secretary	
Karen Berry	Specialist Epilepsy Nurse	
Pauline McEachen	Specialist Epilepsy Nurse	
Aileen McCafferty	Neuropsychologist	
To be recruited May 2016	Regional Neuromuscular Physiotherapist	13 hrs
Jo Clough	Physiotherapist – Intrathecal Baclofen	
Tracy Cameron	Dietitian	0.4 wte for ketogenic diet
Heather Mitchell	Dietitian	
Zoë Whyte	Occupational Therapist	
<b>INVERNESS</b>		
Dr Alan Webb	Consultant Paediatrician with a Special Interest in Epilepsy	5 PAs for epilepsy service Moray/Highland
Christine Sutherland	Medical Secretary	
Dr Linda MacLellan	Consultant Paediatrician	
Dr Lesley Henderson	Consultant Paediatrician	
Kelly McBeath	Specialist Epilepsy Nurse	4 days, part-time
Kirsteen Mackintosh	Specialist Epilepsy Nurse	3 days, part-time
Nikki Strachan	Dietitian	
Judy Shalcross	Dietitian - Wick	
Dr Tracy McGlynn	Psychologist	

NAME	POST	
<b>SHETLAND</b>		
Dr Susan Bowie	GP with a Special Interest	Based at Hillswick Health Centre
<b>ORKNEY</b>		
Catrianna McCallum	Dietitian	
Penny Martin	Physiotherapist	

## North Scotland Child & Adolescent Neurology Network (NeSCANN) Work Plan 2015-2016

RAG status key	Description
<b>RED (R)</b>	The network is unlikely to achieve the objective/standard within the agreed timescale
<b>AMBER (A)</b>	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
<b>GREEN (G)</b>	The network is on track to achieve the objective/standard within the agreed timescale
<b>BLUE (B)</b>	The network has been successful in achieving the network objective/standard to plan

Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at March 2016
Map, develop and agree care pathways  <b>Person-centred, Efficient, Safe</b>	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>Link with national/regional groups to inform existing or new network protocols, standards and referral pathways</li> <li>Develop neurology and epilepsy care pathways for western Grampian/Moray area</li> </ul>	2015-16	M Kirkpatrick H Grossi J Campbell A Webb	Network pathways and protocols continually reviewed. Moray epilepsy pathways now clear and functioning appropriately.  <b>Blue</b>
Map existing clinics and develop and agree new clinic developments  <b>Patient-centred, Efficient, Safe</b>	Agree and establish new clinics according to local needs	<ul style="list-style-type: none"> <li>Agree with multi-disciplinary colleagues any new clinic requirements</li> <li>Identify local lead clinician(s) to be responsible for organising new clinics within individual Health Boards</li> </ul>	2015-16	M Kirkpatrick A Webb A Jollands P Brink ESNs	Clinics continually reviewed. Dr Kirkpatrick appointed Honorary Reader for Dundee University resulting in Dr Brink carrying out more tertiary clinics in Aberdeen & Inverness. Dr Stephen now full-time permanently in RACH and Dr Tyagi carrying out clinics in RACH and Elgin. Baclofen clinic in planning for Grampian.  <b>Green</b>

Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at March 2016
Develop information for patients and families <b>Person-centred, Safe, Efficient</b>	Enhance patient and families' knowledge of service and of disease information	<ul style="list-style-type: none"> <li>Investigate web possibilities to develop network web site</li> <li>Convene a short life working group to identify information and pathways that could be included in the Grampian Clinical Guidance Intranet initially for staff</li> </ul>	2015-16	A Jollands E Stephen C Duncan J Campbell	SLWG being convened. <b>Green</b>
Implement cross-boundary data collection IT system <b>Person-centred, Safe, Equitable</b>	Improve clinical data collection by means of a database for regional network patients to have ability to audit and provide higher quality care to patients	<ul style="list-style-type: none"> <li>NeSCANN clinicians continue to input to SPEN version of the Clinical Audit System (still no system available for NoS patients)</li> <li>Be involved in future discussion on most appropriate systems that could be possible for a regional child health database.</li> </ul>	2015-16	M Kirkpatrick A Jollands C Duncan	Discussion ongoing in NoSPG e-Health Leads' group with regards future most appropriate systems for use in NoS networks. <b>Amber</b>
Audit clinical care <b>Efficient, Safe</b>	Measure performance indicators in children's epilepsy care and review parents' and carers' experiences of service provided	<ul style="list-style-type: none"> <li>Following regional participation in the Epilepsy 12 national audit be involved in discussions on formulation of national KPIs for epilepsy care</li> </ul>	2015-16	M Kirkpatrick A O'Hara A Webb	News on KPIs work awaited from Epilepsy 12 <b>Amber</b>
Review post of regional paediatric neuromuscular physiotherapist (13 hours) to provide support and advice for staff and patients	Ensure new postholder in place by Spring/Summer 2016	<ul style="list-style-type: none"> <li>Set up short life working group to review the existing job description to include additional responsibilities of a former neuromuscular care advisor role to include being a point of contact for neuromuscular patients</li> <li>Agree revised job description with HR</li> <li>Recruit to revised post</li> </ul>	2015/2016	C Duncan A O'Hara M Kirkpatrick	Applications received and interview date confirmed. <b>Green</b>