NHS SCOTLAND

NORTH OF SCOTLAND PLANNING GROUP

NeSCANN Annual Report 2013-14 North Scotland Child and Adolescent Neurology Network

1. Introduction

Welcome to the North Scotland Child and Adolescent Neurology Network (NeSCANN) third annual report, - following yet another very busy year for network staff. The network celebrated its 10th birthday during 2013 which was also marked with a successful joint study day with regional gastroenterology colleagues at Ninewells in October.

Collaborative working between secondary and tertiary professionals across the North health boards continues to develop year on year despite at times some challenging issues. Over the past year services have been delivered and enhanced by the dedication of the network's multi-disciplinary staff in providing the best possible care for their patients. The network is committed to ensuring the sustainability of the network in providing families with patient-centred, safe, effective, efficient, timely, equitable access to services.

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

- provide specialist neurological clinical care of the highest quality
- provide safe and appropriate care as close to the patient's home as possible
- ensure the appropriate skill mix of professionals
- encourage staff training and education
- maintain, develop and empower professional expertise locally and regionally
- work collaboratively with colleagues across Health Board boundaries
- support service delivery and governance
- promote good communication and the sharing of best practice across the North.

2. Background and Network Governance

The Scottish Government National Delivery Plan investment, which is now a recurring resource, commenced in 2008-2011 and provides additional funding across North of Scotland Health Boards, enabling equitable access for patients to multi-disciplinary services across the region. Tertiary and secondary care clinicians support children with epilepsy, neurological and neurodisability conditions across 5 Health Board areas. NeSCANN members work closely with their local teams in Royal Aberdeen Children's Hospital, Tayside Children's Hospital, Ninewells, Dundee and Raigmore Hospital, Inverness, providing care as close to patients' homes as possible. Enthusiastic network members continue to empower and support medical, nursing and Allied Health Professionals to deliver the best quality care.

Telehealth plays a major part in the day-to-day running of the network both for business meetings and review clinical consultations. Video-conferencing is being increasingly used for patient follow-up appointments and contact with chronically ill patients in remote locations, reducing the need to travel long distances.

Dr Martin Kirkpatrick (Clinical Lead) and Carolyn Duncan (Network Manager) continue to support, lead and drive the work of the network across the region in collaboration with local Health Board clinician colleagues and managers.

2.1 Network Links

North of Scotland Planning Group – Child Health

Dr Martin Kirkpatrick and Carolyn Duncan are members of the North of Scotland Planning Group Child Health Clinical Planning Group (CHCPG). The CHCPG drives forward the strategic aims of child health networks in the North in line with national drivers and initiatives and includes representation from Service Managers, nursing and AHP representation from the 5 North Health Boards.

During the year, Dr Kirkpatrick and Carolyn were involved in producing a NoSPG guideline for North of Scotland Framework for Tertiary Paediatric Clinics, which clarifies the roles and responsibilities within specialist networks in relation to key themes such as clinical practice, job plans, education and governance.

Scottish Paediatric Epilepsy Network (SPEN) - Dr Ann O'Hara, Clinical Lead

There are continued strong network links and partnership working with the Scottish Paediatric Managed Clinical Network for Epilepsy, with Dr Ann O'Hara, from Royal Aberdeen Children's Hospital as Lead Clinician and Karyn Robertson as Network Manager of the network. Members of NeSCANN attended the SPEN Members' Day in Stirling in November as well as other interest groups such as educational sessions, SPEN roadshows and family days during the year. Network clinicians have also been involved in discussions and agreement on Midazolam prescribing, various research studies, epilepsy alarms and the RCPCH Child Health Review.

A very successful SPEN Childhood Epilepsy Conference and Family Fun Day took place on 30th November at Transition Extreme in Aberdeen for the benefit of North of Scotland families.

Dr Ann O'Hara reported, 'It was NeSCANN's turn to host a Family Fun Day for SPEN. As the Clinical Lead for SPEN I was keen for it to be held in Grampian and delighted when colleagues here enthusiastically agreed. The conference day is an opportunity for families to meet together socially and also to get more information on a variety of epilepsy related topics. This was provided through some talks, workshops, open question and answer sessions and information stands from a number of voluntary sector organisations.

Talks and workshops for adults covered topics on -

- Epileptic seizures and types of epilepsy syndromes. Families found the videos of great interest and were unaware of the range of seizures.
- Behaviours and learning problems in epilepsy and some very practical advice on how to help which was greatly appreciated.
- Drug and non-drug treatment for epilepsy and teenage issues.

Immediate feedback on the day was very good and I am looking forward to receiving the final evaluation. One family has let us know it was a great venue and very helpful to find out more about epilepsy and what goes on behind the scenes. She found it helpful to meet other families and if possible to get copies of the discussions to share with other family members.'

Scottish Muscle Network

There continues to be links with the Scottish Muscle Network, with network clinicians being closely involved in developments and service improvement updates, e.g. DM1 guidelines, North Star, steroid audit, patient held records and a muscle biopsy pathway. The Scottish Government provided funding for 2 years for Neuromuscular Care Advisors in 2013 to scope the current service available to adult and paediatric neuromuscular patients nationally. The work of the post in the North has been challenging to date due in part to the maternity leave of the Care Advisor. From April 2014 the North of Scotland work will recommence on a full-time basis to scope, agree and establish current and future pathways, standards and guidelines and to look at the educational needs of the workforce.

Scottish National Paediatric Epilepsy Surgery Service

Network staff are involved in and support this national service based in Edinburgh for patients who require epilepsy surgery. The surgery service multi-disciplinary team meetings, with Dr Martin Kirkpatrick leading for North patients, are undertaken monthly by video-conference (but are also open to all regional clinicians who can attend). The meetings are held on a rotating basis between Dundee, Edinburgh and Glasgow, to discuss patients who may go forward for epilepsy surgery either in Edinburgh or at Great Ormond Street in London. Resective neurosurgery for children's epilepsy surgery is carried out in Edinburgh in accordance with an agreement from National Services Division.

3. Updates

3.1 NeSCANN Steering Group

Four steering group meetings by video-conference took place during the year in March, June, September and December. Dr Martin Kirkpatrick chairs the meetings as Clinical Lead, supported by Carolyn Duncan, Network Manager.

The steering group has the remit to direct and approve the objectives of the network's work plan. This has been a challenging year in being able to move forward with work on various topics such as care pathways and new service developments. Nonetheless progress has been made on the designated objectives of our progressive work plan, training and education and research and audit. A welcome network addition has been the development of a new Intrathecal Baclofen clinic in Inverness and a new Headache clinic in Aberdeen.

Significant work has also taken place during the year in updating existing and producing additional structural pieces of work for the network such as a risk register and mission statement documents.

3.2 Staffing

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

The funding for posts provided by the National Delivery Plan (NDP) is now well embedded into services. The regional paediatric physiotherapy advisory role provided by Anne Keddie to paediatric neuromuscular patients and professionals was difficult during the year due to her absence and retiral in September. The post has now been recruited to and regional support, advice and training for patients and professionals will recommence in April 2014.

The network was extremely delighted that Dr Elma Stephen was appointed a permanent Consultant Paediatrician in Grampian at the end of 2013 working 5 PAs for neurology. Dr Stephen is a very enthusiastic member of the network and has already set up a new clinic in RACH.

NDP also provided funding for a physiological technician shared across medical specialties in Grampian. The funding from the post is still intended to be used to set up a paediatric telemetry service in RACH in collaboration with the adult neurophysiology team. In the meantime the Archie Foundation charity has kindly agreed to replace existing ageing equipment for ambulatory EEG recording in Grampian.

3.2.1 Trainee Doctors' Network Experience with NeSCANN

RACH - Dr Vipin Tyagi and Dr Sheik Razak, senior paediatric trainee doctors, have been working with neurology service colleagues at Royal Aberdeen Children's Hospital over the past year. They highlighted they have had excellent opportunities in the department and network to develop their skills in the management of children with epilepsy and other neurological conditions by attending –

- Weekly epilepsy and neurology clinics
- Monthly Neurology Open Day (NOD) meetings with Neuroradiologists and Neurophysiologists.
- NeSCANN steering group meetings.

They have contributed to improving the care of children with epilepsy by involvement in the national Epilepsy 12 audit. They also, together with colleagues, produced a poster presentation on Paediatric transverse myelitis at the British Paediatric Neurology Association annual conference in January 2014 (*Appendix 2)* and a poster presentation on Dravet syndrome has been accepted for the RCPCH spring meeting (*Appendix 3).*

Ninewells – Dr Noha El Tantawi, Dr Rebecca Goldman and Dr Helen Dunne have been working with the Tayside Children's Hospital neurology service during the year.
Dr El Tantawi felt her experience at Ninewells was invaluable. She has now returned to Mansoura University in Egypt where she is enthusiastically developing their epilepsy service having completed all the BPNA PET training courses to allow her to teach on PET courses here and in the Middle East. She also presented at BPNA 2014 and contributed to the Ninewells Brainwave meetings with a number of excellent case presentations and CPD lectures.

Since August 2013, Dr Goldman (neurology) and Dr Dunne (complex neurodisability), part-time trainees, have been participating in teaching, training, audit, research and service development.

3.3 Network Developments

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

3.3.1 Highland/Moray Epilepsy Clinics – Dr Alan Webb, Consultant Paediatrician

Six full day bi-monthly epilepsy clinics delivered by Dr Alan Webb and Epilepsy Nurse Specialists from both Highland and Grampian in Dr Gray's Elgin continued during the year. Patients from the northern end of Moray benefit from being able to have imaging in Inverness as this service is readily available at Raigmore.

Around 50 out-patient appointments were offered of which 10 were new patients. Ten patients had neurophysiology investigations and there was one admission for video telemetry and control of seizures in Raigmore. In addition to the work at clinic the team were contacted on many occasions by families to discuss ongoing seizures and to have medication changes. Discussions will take place in April to review and further develop the service. It is anticipated that improvements and work on care pathways will enhance the service to patients with epilepsy and particularly those with an additional neuro-disability.

3.3.2 NHS Grampian Development - RACH Headache Clinic - Dr Elma Stephen, Consultant Paediatrician

Headache is common in children and particularly in adolescents, with nearly 60% of children reporting having had headaches over periods of time ranging from one month to 'lifetime'*. Appropriate assessment and management of primary headache disorders requires sufficient time during consultation to address the issues which may be contributory to debilitating headache patterns. It was felt that a dedicated clinic to deal with the more complex patients would be better placed to address the needs of this group of patients. The RACH Headache clinic commenced in January 2014 as a consultant delivered new service. This is currently set up as a monthly clinic with a total of 6 patients being seen in each clinic. Referral criteria have been developed (see below) **. Clinic specific resources are being developed including Headache Recording Diaries and information leaflets on migraine and its treatments, tension type headache,

medication overuse headache, etc. Local links have been made with the Adult Headache service in ARI to enable sharing of information resources and address the educational and CPD needs of clinic staff. Future plans include auditing the effectiveness of various management strategies for patients seen in this clinic.

*Reference: Abu-Arafeh et al: Prevalence of headache and migraine in children and adolescents: a systematic review of population based studies. Dev Med Child Neurol 2010; 52: 1088

** Referral criteria (main)

Children with migraine who have failed 2 prophylactic medications Diagnostic uncertainty about the type of headache Headache in children <7 years

3.3.3 Intrathecal Baclofen Service (ITB) – Jo Armstrong, Physiotherapist

A lot of work has been undertaken and liaison locally in Inverness to set up a new dedicated specialist Intrathecal Baclofen clinic to be carried out by Dr Kirkpatrick and Jo Armstrong, Physiotherapist, for the benefit of Highland and possibly west Moray patients. Due to the specialist procedure and ongoing monitoring of this treatment, patients and families previously needed to be seen and treated in Ninewells Hospital, Dundee. The new clinic therefore fulfils one of the aims of the National Delivery Plan and the network by delivering follow-up treatment and care as close to patients' homes as possible.

Over the past year the paediatric ITB service has been making strides in expanding the service throughout the North of Scotland. Jo has been to both Aberdeen and Inverness to present to the paediatric physiotherapy teams on her role as ITB physiotherapist and the pathway for children with tone management problems and those being considered for ITB therapy. Dr Martin Kirkpatrick has been working alongside Dr Lesley Henderson and Dr Linda MacLellan at Raigmore and the first Tone Management/ITB Assessment Clinic will take place in Inverness on 11th March 2014. This is planned to be a twice yearly clinic and it is hoped this can be replicated within NHS Grampian in the future.

Dr Kirkpatrick has also been involved in setting up ITB pump refill clinics in the paediatric Day Case Unit at Raigmore and led a training day with Barry Allan, Medtronic Rep, for staff who will be involved in these clinics. This will reduce the need to travel for children receiving ITB therapy and in one case a 4 weekly visit to Edinburgh will not be required.

Also in Dundee there has been close liaison with the Adult ITB Service, discussing topics such as referral routes, trial pathways, safety protocols, goal setting and planning. I have been working on developing an integrated care document for use during ITB trials which will ensure audit of service efficiency in the future and will be easier to collate. They are also in the early stages of planning a North of Scotland ITB Study Day in August/September 2014 for adult and paediatric services, with the aim of increasing knowledge of ITB therapy and providing a forum for networking and collaboration.

3.3.4 Islands' Clinics

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

3.4 Work Plan

Objectives in the 2013-15 collaborative work plan were progressed during the year (*Appendix 4).* The work plan is continually performance managed with a red/amber/green traffic light system. Objectives include:

- Review the membership of the Paediatric Neurology Steering Group
- Map existing clinics and develop and agree new clinic developments
- Develop information for patients
- Continue to develop education framework
- Implement cross-boundary data collection IT system
- Audit clinical care

There has been detailed discussion on producing and adopting a network Continuing Seizures pathway for patients who fail 2 or more drugs and onwards referral for tertiary opinion. This has now been ratified by the Steering Group. Work has also been undertaken with regards a draft clinical pathway for muscle biopsies in Grampian.

Data management and a fit for purpose IT system that can be accessed from anywhere in the North is still high on the agenda for NeSCANN as well as for other child health networks in the region. There have been several discussions during the year with the system developer with regards the technical aspects of a North of Scotland version of the NSD funded Clinical Audit System (CAS), which have been further complicated due to the interconnectivity and governance arrangements with the national Scottish Paediatric Epilepsy Network (SPEN). SPEN is moving forward with data collection in paper format currently and rolling out Clinical Audit System training in Edinburgh and in Dundee in May 2014.

In addition, funding of the CAS has been delayed due to NoSPG discussions on the Intelligent Region. Ongoing discussions will continue over the coming months however progress is much slower than had been anticipated at the outset. It remains the intention of the network to adopt the system to ensure easy access to information on network patients in the North of Scotland to ensure safe, efficient, person-centred care.

3.5 Training & Education

The network is committed to ensuring staff are well trained and highly skilled and there are a number of educational opportunities available to professionals across the network. 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, brain imaging and neurophysiological investigations.

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

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

3.5.1 Joint Study Day – Neurology and Gastroenterology– 31st October 2013

A very successful Education Day was held in MACHs 2, University of Dundee, Ninewells in October attended by multi-disciplinary colleagues from across 5 centres (over 40 attendees). This was the first time both networks had come together for a joint study day and uniquely the first study day which included the use of video-conferencing technology allowing staff at 5 remote VC sites in Orkney, Shetland, Aberdeen, Elgin and Inverness to take part. It was extremely valuable being able to come together to listen to presentations and to discuss topics that relate to patients who are known to both neurology and gastroenterology networks. Some of the topics presented included, for example,

- Oromotor dysfunction and feeding assessment in the neurologically impaired child
- Fundoplication in children with neurological disease
- Jejunal feeding
- How does it feel? Acknowledging the emotional impact of tube feeding
- The Child with Cerebral Palsy – energy expenditure and growth
- Ideal enteral feeds – from calories to ketones.

Feedback from the event was excellent and the technology worked tremendously well across such a wide geographical area. It is hoped that a further joint study day can be planned for 2015.

3.6 Epilepsy Specialist Nursing (ESN)

Demands on Epilepsy Specialist Nurse resources continue to rise year on year in each of the 3 main centres. A business case for additional ESN resources was completed in Grampian in 2013 however this was unsuccessful despite demonstrating the lack of nursing resource for epilepsy patients in the region.

The service provided by the ESNs is described by many, and evidenced in the recent ESN audit and patient feedback (below) as an extremely good service delivering very high standards of care. This is all undertaken in line with NICE 2012 and SIGN 2005 guidelines however to date there has not been an agreed set of network standards produced for NeSCANN. Work has been undertaken to formally put in place standards in this regard which will be completed shortly.

Patient stories -

New Epilepsy Diagnosis parent feedback

`I felt I had to mention you personally, Karen, as a shining example of what a nurse should be. You are superb at your job.

Just to let you know that there has been an immense improvement since Jane (not the patient's real name) began taking Epilim in modified release form once daily. She

appears much brighter in the morning when she gets up. Absence seizures have greatly diminished. I took her away to Glasgow for a few days to "sightsee" and visit grandparents which she thoroughly enjoyed. She got 37/40 for her science test last week - she's top of the class - I'm amazed at her achieving this.

My only current concern is for her safety crossing roads. I've witnessed her a few times just walking across roads without checking for traffic. I have spoken to her about this but she needs constant reminding. The Epilepsy Specialist Nurse was able to advise Jane's mother with regards safety around traffic. Hopefully the advice helped to improve Jane's mother's confidence levels, when Jane is out and about and will encourage her to let Jane do more and more things.

Please let Dr Clerihew know how grateful we are for her being so prompt in changing Jane's medication regime, because it has really helped. Thank you again for all your support.'

Excellent communication and swift action

A 6 year old boy was referred to the Epilepsy service in Inverness by his GP following a history of becoming vacant for around 5 seconds. The letter was triaged to EEG while waiting to be seen in clinic and mum contacted the Epilepsy service to discuss her concerns (she had heard of the service in the community). This was a great opportunity to reassure and provide information to the child's mother whilst she was waiting for the clinic appointment.

The EEG was able to be carried out prior to the clinic appointment and was diagnostic of Childhood Absence Epilepsy. The epilepsy team were able to briefly meet with the family while across for the EEG. It was suggested that sodium valproate should be commenced and relevant discussions happened on the phone with mum to inform of this. The Epilepsy Specialist Nurse was able to organise a prescription and titration chart to be sent to the family in discussion with the consultant and sodium valproate was commenced. This was all carried out before the day of the clinic appointment.

When the patient was seen at the clinic, he had already started on sodium valproate and Consultant and ESN were able to use the clinic to assess how he was responding and discuss any new concerns the family had.

This example demonstrates very good teamwork between Epilepsy Nurse and Consultant resulting in a diagnosis and treatment plan that was agreed between the family and the team to ensure the patient's care was carried out swiftly and smoothly.

3.6.1 Network Epilepsy Specialist Nurse Service (ESN) questionnaire

The first network-wide ESN questionnaire was undertaken during 2013 looking at the quality improvements that have been made to patients' and families' lives following the introduction of the Epilepsy Specialist Nurse posts from 2004. The audit was handed out anonymously at clinics in Aberdeen, Dundee and Inverness to gain feedback from service users across the network on how they perceived the service and if the service reflected the key components of the NHS Scotland Quality Strategy, i.e. Person-centred, Safe, Effective, Efficient, Equitable and Timely. The results of this study were presented by Ena Cromar at the Scottish Epilepsy Group meeting in Edinburgh in March 2014.

The questionnaire was led by Jo Campbell and Ena Cromar in Aberdeen, together with the Clinical Effectiveness Department in NHS Grampian who assisted in producing the questionnaire and in the analysis of the results highlighted below. ESNs, Karen Berry

and Pauline McEachen in Dundee and Kirsteen Mackintosh and Kelly McBeath in Inverness facilitated distribution in their areas.

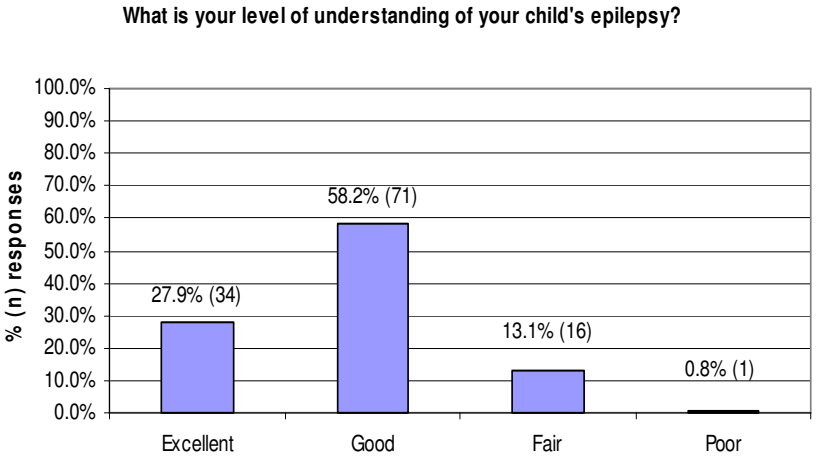
150 questionnaires were distributed in total, 50 in each health board. All questionnaires were distributed and collected during clinic appointments and not sent out by post in the hope of receiving a 100% return.

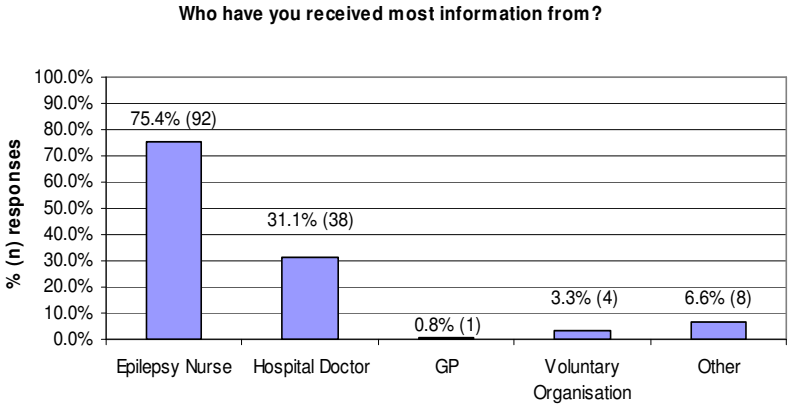
Results

81.3 % of questionnaires were completed and returned.
The majority of children were seen in the major centres; Aberdeen **25.4% (31)**, Dundee **28.7%**, Inverness **25.4%**; however **20.5%** were seen in Elgin, Orkney, Shetland and other areas not specified.

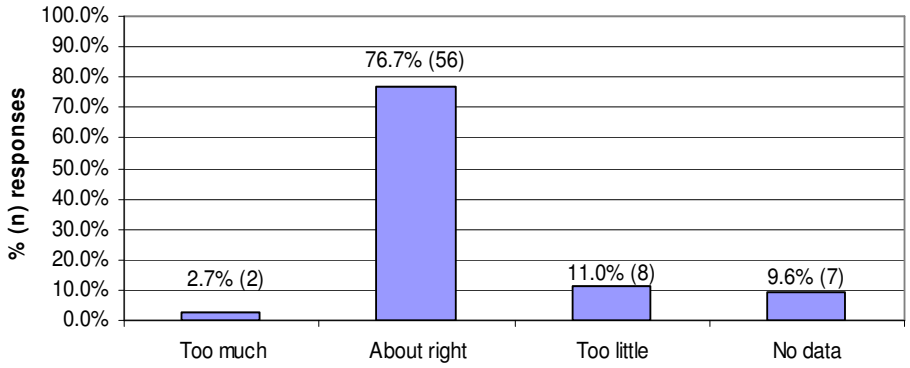
It is reassuring to note that **86.1% (105)** of parents/carers felt they had an excellent or good understanding of their child's epilepsy. This may be due to the consistent distribution of age appropriate information packs by ESNs which are individualised according to syndromic diagnosis and medication if known.

The graphs below give you an indication of some interesting results:

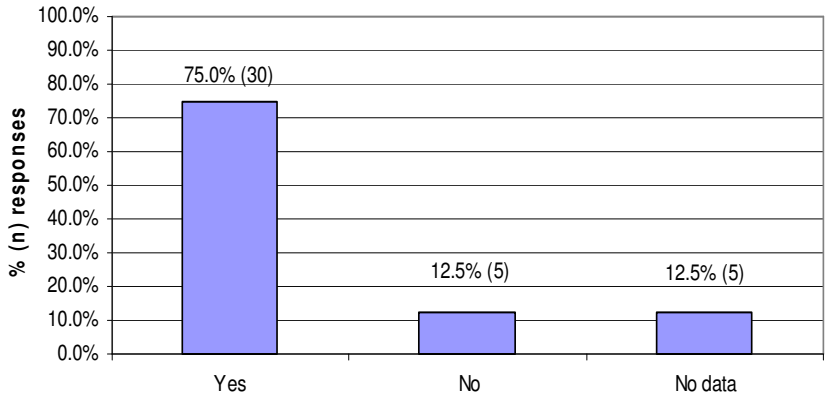




If Yes, around the time of diagnosis, did you receive enough information about epilepsy?



If yes, does the ESN Service meet your and your child's requirements?



Pre-defined Statements	Strongly agree	Agree	Disagree	Strongly disagree	No data
a) I always feel able to contact the ESN for advice regarding my child's epilepsy management	**66.7%** (72)	**28.7%** (31)	**1.9%** (2)	**0.9%** (1)	**1.9%** (2)
b) I feel I am supported to manage my child's epilepsy	**58.3%** (63)	**30.6%** (33)	**8.3%** (9)	-	**2.8%** (3)
c) I feel I am given adequate information from the ESN about my child's epilepsy	**54.6%** (59)	**35.2%** (38)	**5.6%** (6)	-	**4.6%** (5)
d) I feel that the ESN gives appropriate advice	**59.3%** (64)	**36.1%** (39)	**1.9%** (2)	-	**2.8%** (3)
e) It is easy to contact someone in the Epilepsy Team	**50.9%** (55)	**38.0%** (41)	**6.5%** (7)	**1.9%** (2)	**2.8%** (3)
f) The ESN listens to what I say	**63.0%** (68)	**33.3%** (36)	**0.9%** (1)	-	**2.8%** (3)

Conclusion

This audit has been fundamental in establishing a clear picture of the effectiveness of the ESN Service across the network. Numerous positive comments were received from parents and carers; however there were also some minor negative comments showing that further improvements can and will be made in line with current research and best practice guidance to ensure care is person centred, safe and effective. The views of

parents/carers, children and young people will be respectfully considered.

When this audit was carried out some of the Epilepsy Specialist Nurses had only started in post and it is planned that it will be repeated again in 2015/16 to demonstrate that the nurses across the network deliver a quality service.

Improvement Plan - 2014

Dissemination of results - March
Answer phone calls in a timely manner, within 48 hours - April
Discuss mechanisms for supporting children and young people with epilepsy and learning disability educationally and with activities of daily living with Consultant Psychiatrist in learning disability, Neuro-psychologist and learning disability nursing team - April
Contact parent/carer of children and young person who has been diagnosed with epilepsy within 30 working days from initial assessment - April
Improve communication and support offered to/given to educational services - April
Review and re–audit 2015.'

3.7 Allied Health Professionals

Patient Story

Sally presented at the age of 2 years with severe refractory myoclonic epilepsy and was not reaching developmental milestones. She was in foster care with her granny, Mary at the time as her parents, Mark and Ann, had significant problems with drug abuse and had not been able to care for her. However both always tried to attend appointments with Granny and clearly loved Sally and were keen to have her back in their care.

As Sally's epilepsy had failed to respond to anti-epileptic drug therapy the ketogenic diet was considered a good therapeutic option but it was felt it could be difficult to implement. Granny Mary found all the calculations and foods required difficult and overwhelming so wasn't initially keen to try the diet.

Sally was admitted for a trial of the diet in the ward. This proved very successful with a marked reduction in seizure frequency and a dramatic improvement in her behaviour and development. She was eventually discharged with very detailed meal plans for granny to follow. Our Epilepsy Specialist Nurse took time to shop with granny as many of the foods were unfamiliar to her and she still found the whole process overwhelming.

Throughout the period, her parents attended regularly and enthusiastically worked with our ketogenic dieticians. Ann began making Sally special muffins and treats, while Mark got to grips with the computer programme called EKM planner. Her parents attended ketogenic diet workshops in Aberdeen and gradually took on more responsibility for both Sally's diet and care. Sally has now been placed back with her parents and continues to do much better than when on anti-epileptic drug therapy alone. Social services have been unanimous in the view that the dietary therapy has empowered her parents and given them focus. Ann in particular has become creative about meals (and knitting) and granny has been able to confidently hand over Sally's care to her now very able and competent parents. Multi-disciplinary working between clinicians, dieticians, Epilepsy Specialist Nurses and family has seen a whole family benefit from ketogenic diet therapy in some unexpected but positive ways.

(Story gratefully told with permission from both parents and grandmother although names have been anonymised).

4. Research & Audit

4.1 'Epilepsy 12' national audit

A significant amount of work was undertaken in relation to this national audit regarding the care of children with newly diagnosed epilepsy again during 2013, which reported on 12 performance indicators (see table below).

The data provided from the North was an amalgamation of the 3 mainland Health Boards and provided feedback to allow comparisons with other units in the UK. The North of Scotland performed well, with a series of 'positive outlier' results by comparison with the rest of the UK. The full results can be found at *http://www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/epilepsy12-national-audit/results*. Round 2 is currently in progress. Aberdeen, Dundee and Inverness subsequently produced local action plans which were reviewed and follow-up work on items in the unit action plans continues with discussion on progress taking place at quarterly network steering group meetings.

Category Title Performance indicator

1 Paediatrician with expertise in epilepsies	Percentage of children with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' by 1 year
2 Epilepsy Specialist Nurse	Percentage of children with epilepsy, referred for input by an epilepsy specialist nurse by 1 year
3 Tertiary involvement	Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care by 1 year Assessment & Classification
4 Appropriate First clinical assessment	Percentage of all children, with evidence of appropriate first paediatric clinical assessment
5 Seizure classification	Percentage of children with epilepsy, with seizure classification by 1 year
6 Syndrome classification	Percentage of children with epilepsy, with epilepsy syndrome by 1 year Investigation
7 ECG	Percentage of children with convulsive seizures, with an ECG by 1 year
8 EEG	Percentage of children who had an EEG in whom there were no defined contraindications
9 MRI	Percentage of children with defined indications for an MRI, who had MRI by 1 year Management & Outcome
10 Carbamazepine	Percentage of children given carbamazepine, in whom there were no defined contraindications
11 Accuracy of diagnosis	Percentage of children diagnosed with epilepsy, who still had that diagnosis at 1 year
12 Information & advice	Percentage of females over 12 years given antiepileptic drugs, who had evidence of discussion of pregnancy or contraception

The North of Scotland has shown that its service for children with epilepsy compares favourably and indeed to some degree better, in comparison to many other services across the UK. Round 2 of this audit is now in progress and we would wish to be able to demonstrate improvements in care from Round 1 across the UK. The relatively short time between the cycles will be a challenge in achieving this.

For this cycle the Patient Reported Experience Measure (PREM) has been redesigned with colleagues in the University of Dundee. Many more questionnaires will go out to families with the aim of capturing a wide range of parent and young people's views on their care. We see this as a particularly important area of the audit.

Obtaining funding for the Scottish component of a UK-wide audit has become more challenging but it remains very important for the north of Scotland to be able to benchmark its service against the rest of the UK.

To date this audit data has been retrospectively collected. Our aim is to integrate prospectively collected audit data into a fit-for-purpose electronic database.

4.2 Network Epilepsy Monitoring Equipment audit

A network qualitative audit on the use of the above equipment by families is being carried out by Epilepsy Specialist Nurses across the network. This audit identifies the range of monitoring devices families now use and also gives an insight into why parents and carers monitor their children. This was ahead of a Scottish Government audit which will be carried out in 2014 which focuses on epilepsy alarms. Results from the network audit will be published later in 2014.

4.3 Future Audits

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. 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 Sameer Zuberi from Glasgow, who is leading the study, gave a talk to the network about the study at the Brainwave meeting on 3rd March, which was available to Inverness and Aberdeen colleagues by VC. Dr O'Hara, Dr Webb and Dr Kirkpatrick are the local leads for the study in Grampian, Highland and Tayside respectively. 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.

4.4 Academic Presentations and Publications

Scientific Presentations

El Tantawi N, Tasker A, Jollands A, McLellan A, Kirkpatrick M.
Intractable focal motor seizures associated with type 1 diabetes and anti-GAD antibodies – dramatic response to immunoglobulin.
Developmental Medicine and Child Neurology 2014;55(suppl no.1):10
Presented to the British Paediatric Neurology Association, Winchester, January 2014

Gardella E, Larsen J, Wolff M, Schmiedel G, Kirkpatrick M , Barisic N, Depienne C, Troncoso M, Jepsen B1, Nikanorova M, Troncoso L, Bevot A, Hjalgrim H, Benikzky S, Møller RS.

Peculiar interictal and ictal video-EEG features of SCN8A-related epileptic encephalopathy. Accepted for presentation to the International League Against Epilepsy meeting, Stockholm, June 2014.

Razak S A, Tyagi V, Stephen E M, Shah A H
Retrospective Observational Study of Transverse Myelitis in Children
Poster presented to the British Paediatric Neurology Association, Winchester, January 2014

Tyagi V O, Razak S A, Shah A H, O'Hara A, Stephen E M
Dravet syndrome – Don't be deceived by another pre-existing condition
Poster to be presented at the RCPCH spring meeting, Birmingham, April 2014

Peer Reviewed Papers

Ramdas S, Prasad M, Spillane K, Kirkpatrick M. Acute motor neuropathy with pure distal involvement - A case report of multifocal motor neuropathy. *Eur J Paediatr Neurol*. 2013 Feb 14. doi:pii: S1090-3798(12)00261-9.

Ramdas S, O'Colmain U, George ND, Kirkpatrick M. Retinal haemorrhage in an infant following an accidental fall - a case report. *Eur J Pediatr*. 2013 Jun 29.

Williamson S, Kirkpatrick M, Greene S, Goudie D. A Novel Mutation of NKX2-1 Affecting 2 Generations With Hypothyroidism and Choreoathetosis: Part of the Spectrum of Brain-Thyroid-Lung Syndrome. *J Child Neurol*. 2014 Jan 21.

Shetty J, Fraser J, Goudie D, Kirkpatrick M. Aicardi syndrome in a 47 XXY male - A variable developmental phenotype? *Eur J Paediatr Neurol*. 2014 Mar 12

5. Plans for Next Year

The network will work to maintain and add to the services that are provided by the network in 2014/15. Data collection on epilepsy and neurology patients needs to be embedded into everyday practice therefore this will remain a major priority in the coming year.

5.1 Network study day 2014

Following the success of the joint networks study day in 2013, a NeSCANN study day is planned for 18th September 2014 in Aberdeen with the intention of the themes incorporating topics on neurogenetics and neuromuscular conditions. Network staff in Aberdeen will take the lead in organising the event and other regional paediatric clinicians outwith the network from Grampian, Highland and Tayside will also be invited.

6. Key Challenges

6.1 Clinical data – Clinical Audit System

Cross-boundary working brings many challenges and a major challenge for NeSCANN and other networks' members is the management of patients who have to move across health board boundaries to receive treatment. Access to comprehensive clinic data continues to be an issue for all child health networks across the North of Scotland. Progress on adoption of the system has been slower than anticipated due to ongoing North of Scotland Planning Group discussions on the Intelligent Region. However discussions will continue over the coming months and it remains the intention of the network to adopt the system to ensure easy access to information on network patients to ensure safe, efficient, equitable, person-centre care.

7. Looking Ahead

Members of the network continue to work extremely hard to deliver the best quality service to their patients across the region. NeSCANN will continue to develop services together and to build on the excellent collaborative work carried out across the region over the past 10 years. Network members look forward to progressing network developments for the benefit of staff and patients in 2014. Our multi-disciplinary teams of conscientious, hardworking, well trained staff continue to make a big difference and to improve standards of care for patients with a neurological condition across the North of Scotland.

Appendix 1 –

North Scotland Child & 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*	
ABERDEEN		
Dr Ayaz Shah	Consultant Paediatrician	
Dr Elma Stephen	Consultant Paediatrician	Neurology/Dr Gray's, Elgin
Dr Ann O'Hara	Associate Specialist	Also Clinical Lead for Scottish Paediatric Epilepsy Network
Diane Honeyman	Medical Secretary	
Jo Campbell	Specialist Epilepsy Nurse	4 days
Ena Cromar	Specialist Epilepsy Nurse	Part-time
Dr Bruce Downey	Neuro-Psychologist	
Hilary Rennie	Dietitian	
Winnie Taylor	Lead Speech & Language Therapist	
Jo Thomas	Occupational Therapist	
Jane Tewnion	Physiotherapist Neuro-muscular adviser	9 hours
Julie Ralston	Dietitian – Dr Gray's Elgin	
Physiological Technician	0.3 wte of funding will be used to set up VTEM service	
DUNDEE		
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 Linda Clerihew	Consultant Paediatrician	
Sheila Kerr	Medical Secretary	
Karen Lawrence	Specialist Epilepsy Nurse	
Pauline McEachen	Specialist Epilepsy Nurse	
Aileen McCafferty	Neuro-psychologist	
Anne Keddie	Physiotherapist – Neuro-muscular	Retired September 2013
Jo Armstrong	Physiotherapist – Intrathecal Baclofen	Based in Dundee (Kingspark)
Helen Grossi	Ketogenic Dietitian	
Heather Mitchell	Dietitian	
Zoë Whyte	Occupational Therapist	
INVERNESS		
Dr Alan Webb	Consultant Paediatrician with a Special Interest in Epilepsy	5 PAs for epilepsy service
Mandy Craib	Medical Secretary	
Dr Linda MacLellan	Consultant Paediatrician	
Dr Lesley Henderson	Consultant Paediatrician	
Kelly McBeath	Specialist Epilepsy Nurse	Part-time
Kirsteen Mackintosh	Specialist Epilepsy Nurse	Part-time
Nikki Strachan	Dietitian	
Judy Shalcross	Dietitian - Wick	
Dr Tracy McGlynn	Psychologist	Maternity leave from March 2014
Dr Rachel Smith	Psychologist	

SHETLAND		
Dr Susan Bowie	GP with a Special Interest	Based at Hillswick Health Centre

NAME	*POST*	
ORKNEY		
Catriona McCallum	Dietitian	
Penny Martin	Physiotherapist/Practitioner with Special Interest	

Appendix 2 - Poster

Retrospective Observational Study of Transverse Myelitis in Children

S A Razak, V Tyagi, E M Stephen, A H Shah, Department of Paediatric Neurology, Royal Aberdeen Children's Hospital, NHS Grampian

NHS Grampian

Introduction:

Acute transverse myelitis (ATM) is a relatively rare inflammatory clinical syndrome involving spinal cord. We describe the clinical profile, radiological findings and treatment outcomes of 6 children in Grampian area of Scotland, who presented to the Royal Aberdeen Children's Hospital over a 10 year period (2004-2013).

Discussion:

Acute transverse myelitis (ATM) remains a rare condition all over the world with reported incidence ranging from 1-8 per 1 million people in United States per year[1]. Prospective surveillance in United Kingdom revealed incidence ranging from 3-11 per 1 million per year[2].

In the last 10 years, we have managed 6 children who presented to us with ATM and summarise the main clinical features and long-term outcomes below.

Incidence of ATM in Grampian

In Grampian area of Scotland feeding in to Royal Aberdeen Children's Hospital, the incidence appears to be higher compared to that in the published literature.

Year	No of cases (Per children)
2004	2/89332
2011	1/90318
2012	1/90980
2013	2/92487

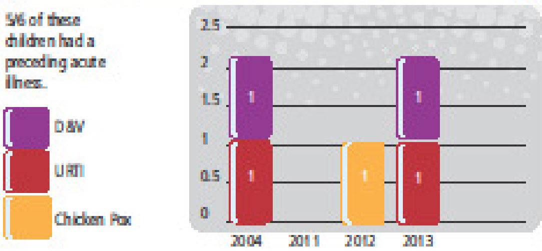
Demographics

The mean age at presentation was 5.06yrs (range 4months-8.5yrs), with a female: male ratio of 2:1

Year	Age	Sex	Ethnicity
2004	4mon	Female	White Scottish
	7mon	Female	White Scottish
2011	8y 5m	Female	White Scottish
2012	7y 11m	Male	White Scottish
2013	7y 9m	Male	White Scottish
	5y 5m	Female	White Scottish

Preceeding Illness

5/6 of these children had a preceding acute illness.



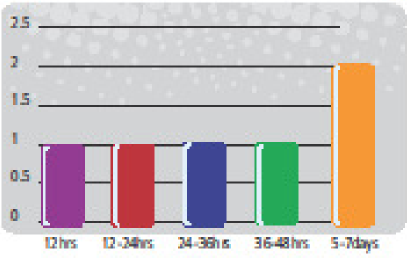
Clinical features

At initial presentation, 5 out of 6 children had motor symptoms such as feeling of legs giving way, unsteadiness, paucity of movement and inability to walk. 4 out of 6 children had sensory symptoms, mainly painful lower limbs. 3 of the children presented with fever at onset and 2 children had encephalopathic features. No patient had evidence of optic neuritis.

- Motor difficulties at presentation (5/6)
- Altered sensation (4/6)
- Pyrexia (3/6)
- Encephalopathic (2/6)

Time presentation to Paralysis

The mean duration of progression from onset to nadir of neurological symptom and signs progression was 2.8 days (range 12hrs-7days).

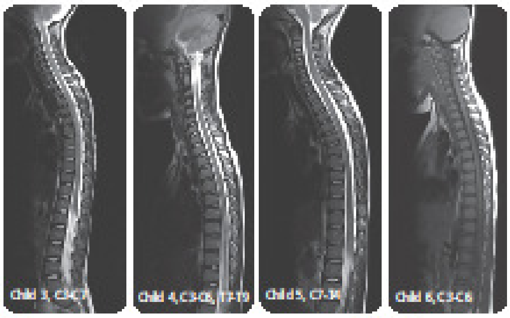


Cerebrospinal fluid analysis & autoimmune workup

Child No	CSF timing	Cytology	Protein	Glucose	Oligoclonal bands	Autoimmune
1	2hrs	Normal	High (Normal by 9 days)	Normal	Not done	Not done
2	3 days	Normal	Normal	Normal	Not done	Not done
3	12hrs	Normal	Normal	Normal	Not done	Aquaporin 4 -ve
4	36hrs	Pleocytosis	Normal	Normal	Negative	Aquaporin 4 -ve, Ganglioside Ab -ve
5	48hrs	Normal	Normal	Normal	Negative	Anti GMI, ANCA -ve
6	48hrs	Normal	Normal	Normal	Not done	Aquaporin 4 -ve

MRI Pattern

The mean time for obtaining MRI spine was 50.6hrs (range 4hrs-7days). 4 showed radiological changes, with the commonest site of involvement being the cervical region.



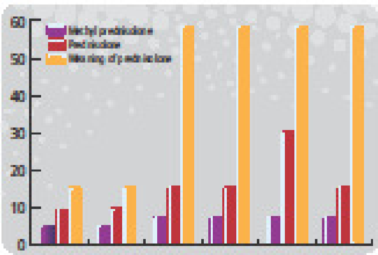
Positive Microbiology /Serology

2 out of 6 children were positive for viral infection, 1 with Mycoplasma infection and 1 child had a high ASO titer.

Child No	Positive Result
1	None
2	Rotavirus
3	Mycoplasma
4	None
5	Adenovirus
6	High ASO titer

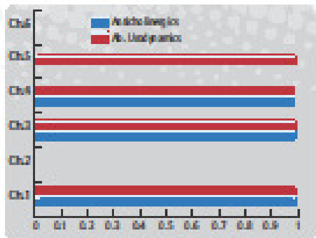
Steroid treatment & Weaning

All children were treated with 3-5 days of intravenous methylprednisolone. Subsequently, all were treated with oral prednisolone for a period varying between 1- 8 weeks.



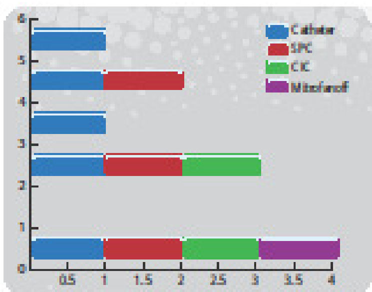
Urodynamics & Anticholinergics

3 out of 6 children had Urodynamic studies performed and all of them had abnormal study. All these 3 children need long term oxybutynin.



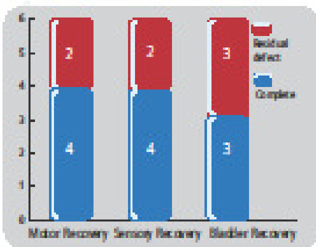
Bladder Intervention

5 out of 6 children were catheterized in the acute stage. 3 children needed suprapubic catheter for long term. Out of these 3 children, 2 children still need intermittent self catheterization and 1 child had Mitrofanoff procedure.



Outcome

At 4 weeks (range 13 days- 4 weeks), 5 out of 6 children were ambulant with or without assistance. 4 out of 6 children eventually had complete motor recovery to full functional ambulation. Urodynamic studies revealed abnormal bladder function in 3 children, who required interventions including suprapubic catheter, temporary vesicostomy and/or the Mitrofanoff procedure. 2 children needed gabapentin for long term pain modulation.



Conclusion

Early aggressive steroid treatment appears to optimise recovery of motor function but long term follow-up suggests that similar[3,4] considerable morbidity remains with the recovery of normal sensation, bowel and particularly bladder function.

Appendix 3 - Poster

Dravet syndrome – Don't be deceived by another pre-existing condition

V O Tyagi, S A Razak, A H Shah, A O'Hara, E M Stephen. Department of Paediatric Neurology, Royal Aberdeen Children's Hospital, NHS Grampian

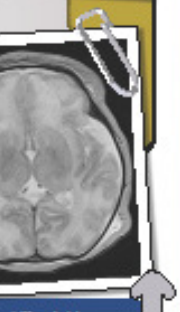
Introduction

Dravet syndrome (DS), or severe myoclonic epilepsy of infancy (SMEI), is a drug resistant epileptic encephalopathy with onset in the first year of life. It is characterised by multifocal clonic, hemiclonic and prolonged tonic-clonic seizures typically provoked by fever and infections. Early development is normal, but signs of cognitive regression appear in the second year of life often accompanied by convulsive status epilepticus1. Nearly 80% of patients are associated with mutation in SCN1A gene which encodes for alpha subunit of voltage gated sodium channel2. Early recognition and diagnosis of DS and management with appropriate anticonvulsants may reduce the seizure burden and improve long-term developmental outcome3.

Early diagnosis needs a high index of suspicion, particularly in children who already have a pre-existing condition that predisposes to epilepsy but have unexplained atypical features.

Case Discussion

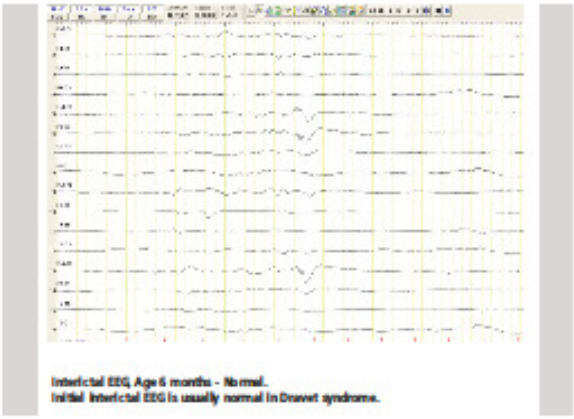
We describe the case of a 2 year old boy who was born at term by emergency caesarean section in view of reduced foetal movements and pathological cardiotocograph. His cord arterial pH was 6.7 and APGAR score of 0 at 1 min and 1 at 5 and 10 minutes. He developed electro-clinical seizures on day 1. Seizures subsided quickly with phenobarbitone which was then stopped on day 5. MRI scan of brain on day 6 showed ischaemic injury predominantly to white matter in watershed areas with increased T1 signal over both lentiform nucleus. Despite a stormy early course, he made a good recovery and was discharged at 2 weeks on oral feeding.



MRI Brain, age 6 days – Restricted diffusion in frontal lobes and basal ganglia.

MRI Brain, age 6 days – Diffuse bright increased T2 signal in white matter and heterogeneous basal ganglia signal..

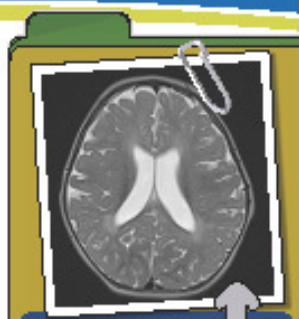
His early neurodevelopment was relatively preserved. However seizures occured when he was 5 months old. Initially seizures consisted of multiple brief multifocal seizures during periods of intercurrent illness. Initial Interictal EEG was normal. In view of focal seizure, he was commenced on carbamazepine. However seizures got worse on carbamazepine and evolved over next 3 months into multiple episodes of status epilepticus during febrile illnesses. His neurodevelopment plateaued. Carbamazepine was changed to sodium valproate. These refractory seizures were initially attributed to post-asphyxial insult to brain at birth.



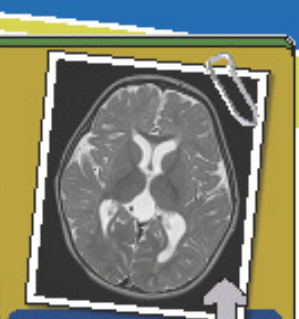
Interictal EEG, Age 6 months – Normal.
Initial Interictal EEG is usually normal in Dravet syndrome.

MRI brain was repeated at 11 months and it showed persistent patchy white matter changes, but there were no specific areas of cortical damage to account for severe refractory epilepsy. His neurodegression, particularly in cognitive and language skills became quite obvious after the first birthday. All this prompted us to look for an alternative aetiology.

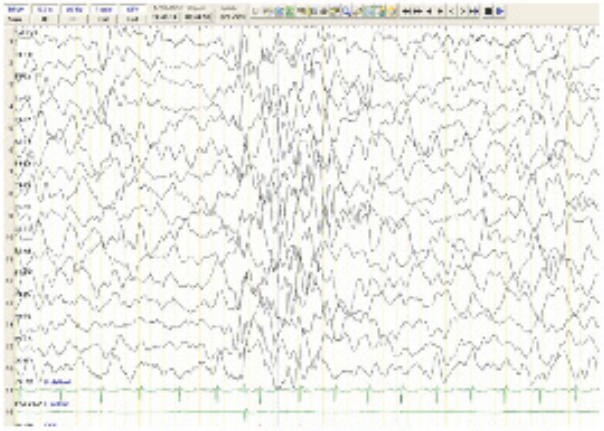
In view of recurrent episodes of status epilepticus usually in the context of intercurrent illness with or without fever, genetic testing was done for Dravet syndrome. It detected a pathogenic mutation in SCN1A gene and confirmed our diagnosis.



MRI Brain, age 11 months – Patchy periventricular white matter change.



MRI Brain, age 11 months – Loss of white matter posteriorly.

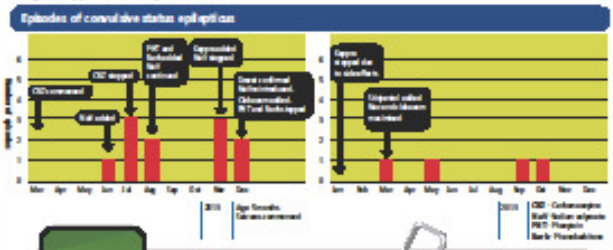


Interictal EEG, age 10 months – Burst of generalised high amplitude slow waves mixed with spike

In the light of new diagnosis, antiepileptic drug therapy was optimised for Dravet syndrome. A combination Stiripentol, Valproate and Clobazam has dramatically reduced the seizure burden and hospital admissions, although cognitive progress has remained slow.

Correct diagnosis has been vital in informing us to avoid antiepileptic drugs like carbamazepine, lamotrigine and phenytoin that make seizures worse in Dravet syndrome. It also helped in counselling carers regarding not only prognosis, but also avoidance of triggers.

Graphs depicting decrease in episodes of convulsive status epilepticus after optimising antiepileptic drug therapy for Dravet syndrome.



Conclusion

Dravet syndrome should always be considered in children presenting with refractory polymorphic seizures in infancy especially when they have prolonged febrile seizures. This case report emphasises the need to constantly review the aetiology and syndromic diagnosis in refractory epilepsy even with an apparent underlying cause, especially if there are unexplained atypical features.

1. Dravet C, Bureau M, Oguni H, Fukuyama Y, Cokar O. (2005) Severe myoclonic epilepsy in infancy (Dravet syndrome). In Roger J, Bureau M, Genton P, Tassinari CA, Wolf P (Eds) Epileptic syndromes in childhood and adolescence. 4th ed. John Libbey Eurotext Ltd. Montrouge; pp 89–113.
2. The spectrum of SCN1A-related infantile epileptic encephalopathies Louise A. Harkin, Jacinta M. McMahon, Xenia Iona, Leanne Dibbens, James E. Pelekanos, Samuel M. Zuberi, Lynette G. Sadleir, Ilse Andermann, Deepak Gill, Kevin Farrell, Mary Connolly, Thorsten Stanley, Michael Harbord, Frederick Andermann, Jing Wang, Sat Dev Batish, Jeffrey G. Jones, William K. Seiger, Alison Gardner, The Infantile Epileptic Encephalopathy Referral Consortium, Grant Sutherland, Samuel F. Berkovic, John C. Mulley, Ingrid E. Scheffer, Brain (2007), 130, 843–852
3. Millichap JJ, Koh S, Laux LC, Nordli DR Jr. Child Neurology: Dravet syndrome: when to suspect the diagnosis. Neurology. 2009 Sep 29;73(13):e69-62.

North Scotland Child & Adolescent Neurology Network (NeSCANN) Work Plan 2013-2015

Objectives	Outcome	*Tasks*	Timescales	Lead Professionals	Progress at February 2014
Review the membership of the Paediatric Neurology Steering Group (RAG status: Amber) *Effective, efficient*	Review the group membership and produce an up-to-date work plan	• Produce a network mission statement • Update annual work plan	2013-14	M Kirkpatrick C Duncan	Mission statement worked on and work plan review ongoing
Map, develop and agree care pathways (RAG status: Amber) *Person-centred, safe, efficient*	Develop North region care pathways to ensure consistency across the network, enhancing links to national/other regional networks	• Identify existing care pathways and any gaps • Link with national/regional groups to inform existing or new network protocols, standards and referral pathways • Develop neurology and epilepsy care pathways for western Grampian/Moray area	2013-15	A Jollands H Grossi J Campbell J Armstrong A Webb	Work complete regarding Continuing Seizures pathway.
Map existing clinics and develop and agree new clinic developments (RAG status: Amber) *Person-centred, safe, efficient, equitable*	Agree and establish new clinics according to local needs	• Map existing cross-boundary clinics • Agree with multi-disciplinary colleagues proposed new clinic requirements • Identify local lead clinician(s) to be responsible for organising new clinics within individual Health Boards, for example, Baclofen clinics in Inverness, Elgin and Aberdeen	2013-15	M Kirkpatrick A Shah A Webb A Jollands ESNs	Discussions ongoing and dedicated Baclofen clinic now set up for Inverness
Develop information for patients (RAG status: Red) *Person-centred, equitable*	Enhance patient/families' knowledge of service and of disease information	• Develop patient information and involvement leaflets • Investigate Web possibilities to develop network website	2013-15	A Jollands H Grossi J Campbell J Armstrong	

Objectives	Outcome	*Tasks*	Time-scales	Lead Professionals	Progress at February 2014
Continue to develop education framework (RAG status: Amber) *Effective*	Continue to review the training needs of network staff and describe a planned curriculum of Continuing Professional Development	• Identify service and staff needs • Review educational opportunities – local/ regional/national • Collaborate with the NoS Gastroenterology network to organise a joint study day in October 2013	2013-15	A Jollands C Duncan J Campbell E Cromar	Joint gastro/neurology networks event took place on 30 October 2013 at Ninewells, Tayside
Implement cross-boundary data collection IT system (RAG status: Amber) *Effective, safe, timely*	Improve clinical data collection by means of a Clinical Audit System to have ability to audit and provide high quality care to patients	• Gain NoSPG agreement to develop and to provide funding so that NeSCANN can input to a North of Scotland version (which includes the SPEN version with NoS neurology data sections)	2013-15	M Kirkpatrick A Jollands C Duncan	Implementation delayed due to Intelligent Region discussions ongoing at NoSPG.
Audit clinical care (RAG status: Amber) *Efficient, effective, equitable*	Measure performance indicators in children's epilepsy care and review parents' and carers' experiences of service provided	• Participation in and collation of data for the Epilepsy 12 extension national audit during 2013/14 • Each unit to work on local action plans and discuss progress at network steering group meetings	2013-14	M Kirkpatrick A Shah A Webb	Work ongoing with Tayside local action plan reviewed

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