

NeSCANN

*North of Scotland Child and
Adolescent Neurology Network*

Annual Report 2020-21



CONTENTS

1.	Introduction	2
2.	Network Governance	2
3.	Service Delivery Updates	3
3.1	Staffing	4
3.1.1	Covid – Reflections from a Shielded staff member	
3.2	Work Plan	7
3.3	Network Service Mapping	
3.4	Intrathecal Baclofen Service	8
3.5	Paediatric Neuromuscular Update	
3.6	Ketogenic Diet Service	9
3.7	Out of Hours Telephone Advice Rota	13
3.8	Patient Stories	
4.	New Developments	15
4.1	Clinical Pathways	16
4.1.1	VNS (Vagus Nerve Stimulation) pathway	
4.1.2	Management of Spina Bifida/Foetal Surgery pathway	
4.1.3	CBD (Cannabidiol) Network guideline	
4.2	New Video-telemetry service in RACH	
4.3	vCreate – information sharing system	17
5.	Training and Education	
5.1	Tayside educational highlights	18
5.2	Grampian educational highlights	
5.3	Epilepsy Specialist Nurse training for emergency medication Administration	19
5.4	National Competencies for Paediatric ESNs	
6.	Research & Audit	19
7.	Key Challenges	20
8.	Looking Ahead	20
	Appendices	
	Appendix 1 – Staff List	
	Appendix 2 – Network Work Plan	

1. Introduction

Network staff have experienced many challenges over the past year due to the global pandemic and this has highlighted the crucial role that the network plays in enabling the delivery of safe, effective and equitable care by collaboration throughout the North of Scotland.

From February 2020 the national priority was to prepare for and cope with the Covid-19 impact to services provided to paediatric neurology and epilepsy patients and their families and some services were paused (e.g. Vagus Nerve Stimulation and Baclofen pump implants, MRI and EEG scans). Patient care was never compromised due to Covid-19 but it felt like a very strange landscape as we all picked our way through a very different, rapidly changing environment. Thankfully as paediatric patients are not as susceptible to contracting Covid-19, very few patients tested positive however some asymptomatic children who came into hospital for other procedures had tested positive across Scotland.

Network out-patient work was still able to be undertaken using the telephone and new video media with team video calls being the 'new normal' which worked very well. Clinicians had to very quickly get used to the Scottish Government's 'Near Me'/'Attend Anywhere' clinical appointments video call system which mainly took over from routine hospital out-patient appointments at the start of the pandemic and which meant patients were still able to be seen albeit virtually. There was still capacity to see patients face-to-face in designated hospital Green zones or hubs if this was urgent or felt appropriate.

Routine MRI scans and routine EEGs were also paused and unfortunately waiting lists grew considerably over the period.

As hospital services return to a new normal, no-one could have predicted that the pandemic would have continued for as long as it has. Network staff must be thanked for their amazing capacity to deliver safe, effective services and for continuing to facilitate the sharing of first-class skills and knowledge to ensure patients received the best care possible even during these adverse times.

2. Network Governance

Since 2001, the NeSCANN has been delivering neurology, neurodisability and epilepsy in-patient and out-patient services e.g. medical, nursing, physiotherapy, dietetics and neuropsychology, to paediatric patients with neurological conditions in NHS Tayside, NHS Grampian, NHS Highland, NHS Orkney and NHS Shetland.

Network clinicians are committed to ensuring the sustainability of neurology services across the North of Scotland and specialist neurology and epilepsy services are delivered to provide person-centred, efficient, timely care. Multi-disciplinary teams of highly experienced clinicians are based in Royal Aberdeen Children's Hospital, Tayside Children's Hospital, Dundee and Raigmore Hospital, Inverness.

The main aims of the network are to

- provide patients and families with patient-centred, safe, effective, equitable care as close to patients' homes as possible.

- ensure provision of a reliable system of clinical care such that the child and their family see the appropriate professional in a timely manner for the most effective and safe care.
- ensure an equitable system of care taking into account the geography of the North of Scotland.
- ensure the development of local professional expertise across the network.
- participate in national and local audits and outcome measures for the benefit of network patients.
- ensure multi-disciplinary training and education opportunities for staff working within the Network.
- take part in local governance and multi-disciplinary case discussion meetings.

Network Leadership

There was a gap of several months at the start of the period due to Professor Martin Kirkpatrick stepping down as the NeSCANN Clinical Lead. Martin had been the founder member of the network and he led the network with great skill and integrity for nearly 20 years. His wealth of knowledge and experience is sorely missed but we wish him a long and healthy retirement.

The network is accountable to the NHS Scotland North Regional Team (formerly the North of Scotland Planning Group) and links into the Child Health Clinical Planning Group. From 1st October 2020 a new style of clinical leadership and way of working came into being with the appointment of 3 Joint Clinical Leads by the North of Scotland Regional Team. Many discussions took place on systems leadership, a concept where staff take individual responsibility for working within a system, which in this case is NeSCANN. The network was consulted prior to agreeing to proceed with this model and consequently Jo Campbell (Paediatric Epilepsy Specialist Nurse), Dr Alice Jollands (Consultant Paediatric Neurologist) and Dr Elma Stephen (Consultant Paediatric Neurologist) were appointed as Joint Clinical Leads for a period of 2 years in the first instance. Carolyn Duncan continues as Network Manager supporting the network across the region in collaboration with local colleagues and managers.

Training, case discussions and peer review meetings were able to continue virtually during the year. A highly skilled multi-disciplinary team continues to be very important to patient care and there continues to be a number of educational opportunities available across the year. Monthly Brainwave days (Dundee) and NOD (Neurology Open Days) in Aberdeen to discuss complex cases, EEG results and provision of educational sessions are open to any member of the network and multi-disciplinary teams and trainees. Lunchtime case discussions with local paediatricians take place in Inverness as required when Dr Brink provides monthly tertiary clinics at Raigmore (face-to-face clinics were suspended during the pandemic in NHS Highland but Near Me clinics were delivered). Two full neurophysiology and neuroradiology days per year which include education sessions also take place in Inverness.

3. Service Delivery Updates

Across the North of Scotland most patients were seen in virtual clinics or spoken to on the telephone due to the pandemic. General admissions to the hospitals were less than normal. MRI lists have now been able to return however waiting lists continue to be a concern. Elective MRI scans under Melatonin sedation were set up, as a QI project in NHS Grampian and also in NHS Tayside these are being successfully used to

reduce waiting lists in children. Video telemetry was not possible in Dundee as the HDU was not available due to the volumes of patients requiring high dependency care.

Aberdeen staff were successful in setting up a video telemetry service from HDU in RACH. Equipment was installed in February 2020 and is now fully functional. This new development will double the capacity in the provision of video telemetry across the region once services return to normal.

3.1 Staffing

During the year we were sorry to lose Dr Noha El Tantawi from Ninewells who returned home to Egypt. But we were delighted to welcome Dr Paul Eunson, Locum Consultant Neurologist, to the team on a part-time basis. Paul had worked in RHSC Edinburgh for many years before his retirement and brings a tremendous wealth of knowledge and experience to the team.

Sadly as well as Prof Kirkpatrick retiring, we had 3 further retirements during the year. We said farewell to Ena Cromar, Paediatric Epilepsy Specialist Nurse in RACH and Dr Linda MacLellan, Consultant Paediatrician with a neurology and neurodisability special interest in Raigmore. Ena had over 40 years' experience as a paediatric nurse and 10 years as a Paediatric Epilepsy Specialist Nurse. Linda had worked tirelessly in Highland for many years and had a wealth of experience working in Inverness and in the remote and rural locations of the North of Scotland. Dr Karen Naismith who was the lead for neuromuscular patients in Tayside for many years also retired during the year. We will miss Karen, Ena and Linda greatly but wish them well in their well earned retirements.

In 2020 Dr Shoaib Khan was appointed Consultant Paediatrician with a special interest in epilepsy and he is working between RACH and Dr Gray's in Elgin. Shoaib is a great asset to the RACH team.

Please see the network staff list attached at Appendix 1.

3.1.1 Covid – Reflections from a Shielded staff member working through the pandemic

When the pandemic started, I was informed by Scottish Government that I would have to shield. Apart from a brief period over December, I spent from April 2020 until May 2021 working from home.

So what have I learnt?

When required, the NHS can mobilise and facilitate remote working.

1. I was rapidly enabled to access all clinical systems essential to patient care from home
2. Although we had already begun to use Near Me in a limited way, the remote consultation system was rolled out rapidly and expansively to good effect.
3. The introduction of Microsoft Teams meant that anyone could participate in educational opportunities, deliver teaching and support colleagues and trainees in a more inclusive way than previously possible.

4. IT departments and management became much more flexible and responsive. There was less resistance to change and fewer hoops to jump through when trying to get things set up and running.

As a previously shielded staff and network member I would like to thank the NHS and IT departments in particular for making this all possible.

This positivity should be harnessed to progress many of the frustrations caused by cross boundary working in the North. Yes – it is possible!

Reflections on delivering remote care:

I was able to deliver a significant amount of care and support to families remotely. Families were very appreciative as many of the children were vulnerable and parents were worried about exposing them to COVID. Many had been shielded like me and we were able to share the highs, lows and worries of this experience together.

Near Me offered the added benefit of 'seeing' patients and their families and in some instances I was able to ask parents to demonstrate some clinical features remotely to reassure both families and myself that things were OK. I even had occasion to observe typical 'funny turns' during consultations – this helped differentiate between less concerning non-epileptic events and more worrisome ones that needed further evaluation.

I also asked myself if there was an evidence base or guidelines on how best to use this new way of working. I worried about the potential of missing serious clinical problems as a consequence of not being able to see a patient in person or examine them properly.

There is a helpful body of research and some evidence around the delivery of telemedicine. There is also some specific information around delivering neurological services (mainly in adult care in the USA with chronic care). Most telemedicine services however are delivered in the context of a clinical facilitator (GP, general paediatrician or specialist nurse) who is with the patient. Physical examinations, specialist investigations, etc, are facilitated while the remote consultant/clinician is able to view and support the local team and patient. This type of care has been shown to be safe, effective and a positive experience for all.

I had an opportunity to engage in this way of working by conducting ward rounds on a regular basis – my colleagues wheeled me around on a lap top from patient to patient. I got to take histories directly from parents and children, observe detailed examinations and jointly agree plans with staff and families on the wards.

(Side note – when 'wheeling' your consultant around from one patient to another remind them to shut their eyes! Particularly if they suffer from motion sickness!).

Essential: I was lucky enough to know the teams working on the wards. This is essential if there is to be mutual trust and cooperation in the best interest of patients. I was also familiar with the environment. This re-enforced a personal view that remote working is possible but that there has to be investment in face to face working and team building as a prelude to developing this kind of service delivery.

Near Me (Attend Anywhere):

This system is designed to deliver care directly between clinician and patient. Patients and families were delighted that they did not have to travel to hospital and have been overall very positive about this way of delivering care. It has lessened the need to travel and proved less disruptive to their families' lives.

Published evidence around this way of working relates to patient and clinician satisfaction. (Less travel time, no hassles with parking, less costly and less disruptive to work/life). There are also obvious added advantages in the context of disability.

There is however no published data on risks or clinical outcomes. This was of grave concern to me. I could not be confident that troublesome clinical features such as raised intracranial pressure, significant tone related issues or concerning new neurological signs had not eluded me.

Working with colleagues we began to develop pragmatic guidelines to minimise risk. Much research is still required to support the delivery of safe care in this way.

Personal reflections:

1. All new patients should probably be seen face to face to facilitate a thorough physical examination and accurate anthropometric measurements including head circumference. This is also vital in establishing a good rapport with children and families.
2. Follow up appointments via Near Me work very well when we have a good relationship with the child and family. Near Me is particularly helpful for the follow-up of children with epilepsy and primary headache disorders.
3. When changing neurology is anticipated and developmental reviews are required, face to face appointments remain important. This is especially so for the very young infant and child, evolving cerebral palsy or progressive neurological disease. Physical examination cannot be dispensed with in this context! How often do we need to deliver face to face appointments versus remote reviews? How do we measure outcomes? What outcomes do we measure? Should there be a specific Datix process to flag up missed diagnosis or delayed diagnosis? So many questions....
4. This technology is advantageous for those who 'have'. But disproportionately disadvantages those who don't. Problems encountered include lack of decent Wi-Fi access in rural and remote settings and lack of mobile data or appropriate IT equipment. I also wondered how families felt about us being able to see directly into their homes! (I did however have the privilege of meeting some family pets!).

Across the country, Near Me showed that clinicians were able to deliver a remote service without actually seeing patients in person. From a network perspective we will however need to do more work exploring the pros and cons of providing a blended model of seeing patients virtually and in person. The development of evidence based guidelines and patient pathways must be mindful of patient safety including the best timescales for patients to be seen either via Near Me or face to face in the future.

Finally, I would like to thank all my wonderful colleagues at Ninewells and across the network for all their support during a very protracted physical absence – I love being back in the office! Being back has reinforced my belief in 'Ubuntu' – a Zulu concept – 'I am because we are'.

Dr Alice Jollands
Consultant Paediatric Neurologist

3.2 Work Plan

Although we were able to hold quarterly network meetings by Teams during the year, it was challenging getting the time to work on our network's work plan due to the pressures of the pandemic, please see *Appendix 2*. The work plan is continually performance managed by a red/amber/green/blue status system.

Pieces of work included –

- Development of network pathways and protocols – ambulatory EEG leaflet was completed, the network Increased Tone Pathway was shared across the Health Boards and modified to take into account local differences in provision of service. A draft business case was updated several times during the year for a Consultant Epilepsy Nurse and this was supported at the North of Scotland Child Health Clinical Planning Group. However agreement from senior management in the North as to how this business case should progress through the regional management structures is still awaited.
- There was network involvement in a national Risks in Epilepsy questionnaire which was developed during the year for patients and families. Information has been collated with the results due shortly.
- Development of an Out of Hours Consultant Telephone Rota – this has been worked on during the year and it is hoped that this will be up and running in late 2021.

Regional collaboration continues on network protocols and pathways, e.g. continuing seizures, video telemetry and Vagus Nerve Stimulation (VNS). For a number of years there has been very good collaboration with the national networks; the Scottish Paediatric Epilepsy managed clinical Network (SPEN), the Scottish Muscle Network (SMN) and the national Neurosurgery Managed Service Network (MSN). North network clinicians hold formal positions in these networks and continue to collaborate closely with colleagues in the Central Belt which maintains and strengthens the partnerships across Scotland.

Several network staff were involved in the development of SIGN 159, Epilepsies in children and young people: investigative procedures and management: A national clinical guideline (May 2021) - <https://www.sign.ac.uk/our-guidelines/epilepsies-in-children-and-young-people-investigative-procedures-and-management/>. Dr Stephen and Jo Campbell were in the guideline development group and Dr Jollands, Dr Brink and Dr Webb were specialist reviewers.

In addition to the above, a lot of work continues to be undertaken by network staff who work collaboratively on national projects, research and audit and care pathways with SPEN, the Scottish Muscle Network (SMN) and the national Neurosurgery Managed Service Network. Network staff were also involved in national discussions on patient access to a number of new expensive medications for spinal muscular atrophy patients.

3.3 Network Service Mapping

A large piece of collaborative work was undertaken during the year to map services and workforce and to identify gaps and bottlenecks for all of the network services provided for neurology and epilepsy across the region. However access to data

continues to be challenging in some health board areas. This is a working document but has highlighted the areas to work on for the next year.

This mapping exercise identified a gap in access to neuropsychology services in Highland and the requirement for further assessment of support required for Highland clinics due to staff retiring and caseload configuration. It has also been noted that often access to neurophysiology technician cover in Aberdeen and Dundee can be challenging with several vacancies particularly in Aberdeen Royal Infirmary. The issue of a shortfall in the workforce nationally and the fact that fewer people are applying for training have been highlighted with Scottish Government.

3.4 Intrathecal Baclofen Service

During the pandemic the service was severely restricted due to the pandemic and there have been no Intrathecal Baclofen trials taking place during the 2020-2021 period. Both from the limited availability of ward space in Tayside Children's Hospital, HDU beds and also the decision of parents to protect and shield their vulnerable children. There are a number of children waiting for trial and hopefully these will begin over the next few months.

When Prof Martin Kirkpatrick retired, Dr Philip Brink took over to lead on this network service, with support from Dr Paul Eunson. MDT Tone Management clinics across the North of Scotland have also been postponed over the pandemic, with Consultants seeing children with complex tone management issues in their regular clinics. As services are now remobilising ITB is something that we will aim to get back to.

Dr Brink has re-instigated the Scottish ITB Seminar group and it is hoped that there will be a face-to-face meeting in October 2021 to continue the productive work and networking that has taken place across Scotland in the past.

Jo Clough, Physiotherapist

3.5 Regional Neuromuscular Physiotherapist & Care Advisor Update

During COVID19 lockdown the majority of children with neuromuscular children were shielding and this was a very worrying and challenging time for parents with an increase in calls for advice and support especially regarding behaviour within the Duchenne Muscular Dystrophy (DMD) population.

As with many specialties, Muscle clinics across all areas were cancelled, postponed or performed virtually. Thankfully as restrictions lift re COVID 19 the majority of children with neuromuscular conditions have come out of shielding and returned to full time schooling. However a few parents are still concerned about the risk of infection and transmission and have continued to keep their children away from school and be taught at home virtually. Hopefully with the positive feedback from study results in America involving vaccination of children 12-16 years of age, the vaccine will become available to vulnerable young people in the UK, and they will be able to access the vaccine and feel confident to return to school.

Muscle clinics across all areas are back to face-to-face contacts, with some appointments remaining virtual through parental request or due to patient/parent illness. I have been able to attend NHS Highland clinics face to face since February this year and have also linked in virtually with Aberdeen and Tayside clinics as needed.

Neuromuscular assessments are also now back to being face to face which makes assessment of muscle power and joint range far easier!

In March 2021 we had 119 children across the North of Scotland with a Neuromuscular condition. A number of our children with Spinal Muscular Atrophy types 1, 2 and 3 are on the intrathecal drug, Nusinersen and this is being administered at tertiary centres in Aberdeen, Dundee, Edinburgh and Glasgow. But we now also have a few children with type 2 SMA taking the oral medication Risdiplam which negates the need to travel for some children and is obviously less invasive. It is early days to see how beneficial this is for our older children, but hopefully it can maintain the skills they have and delay any deterioration. We also have the 1st NEScANN patient to have received Zolgensma gene therapy for SMA, as a one off IV infusion. Two patients in NeScANN have now been treated with Zolgensma, the first 2 patients anywhere in Scotland.

Dr Linda MacLellan, Consultant Community Paediatrician with the Lead for Neuromuscular conditions in the Highlands retired at the end of March 21 and Dr Gavin Cobb has taken over as the Neuromuscular Lead and is a very welcome asset. Dr Karen Naismith also retired earlier this year and Dr Gemma Robertson, Consultant Paediatrician for Children with Complex Disability has taken over within Tayside working alongside Dr Ann Scott and I look forward to working with her as well.

I have recently circulated a Neuromuscular Newsletter to all localities highlighting interesting links, stories and facts pertaining to neuromuscular conditions. Hopefully this was useful, and I will ensure that information is sent out in a timely manner. It has been sent to the physiotherapy leads, but if anyone else would like a copy, please just email me at: julie.burslem2@highland.gov.uk or julie.burslem2@nhs.scot. This is a work in progress and any suggestions would be gratefully received.

My small research study on the learning and cognitive issues often linked with DMD is nearing completion. There is a PowerPoint presentation suitable for schools and parents to give an insight into this area and also a slightly more in-depth one for clinicians and AHPs and this has been piloted on schools and clinicians within the Highlands. In addition, I have been working with the Educational Psychology team in the Highlands looking at a resource pack for schools to help support children with a diagnosis of DMD from an educational perspective. This has taken a bit of back step due to COVID 19 but will hopefully be completed shortly. A far more in-depth project is the BIND project mentioned below.

The BIND project – Brain Involvement in Dystrophinopathies. This is a large international project to study dystrophin in the brains of people with DMD and Becker Muscular Dystrophy (BMD) and will run over 48 months (started end of January 2020). It now has a web page, and you can able to follow the progress and access the results when published on: [About • Brain Involvement in Dystrophinopathies \(BIND\) \(bindproject.eu\)](http://bindproject.eu).

Julie Burslem

Regional Neuromuscular Paediatric Physiotherapist and Care Advisor

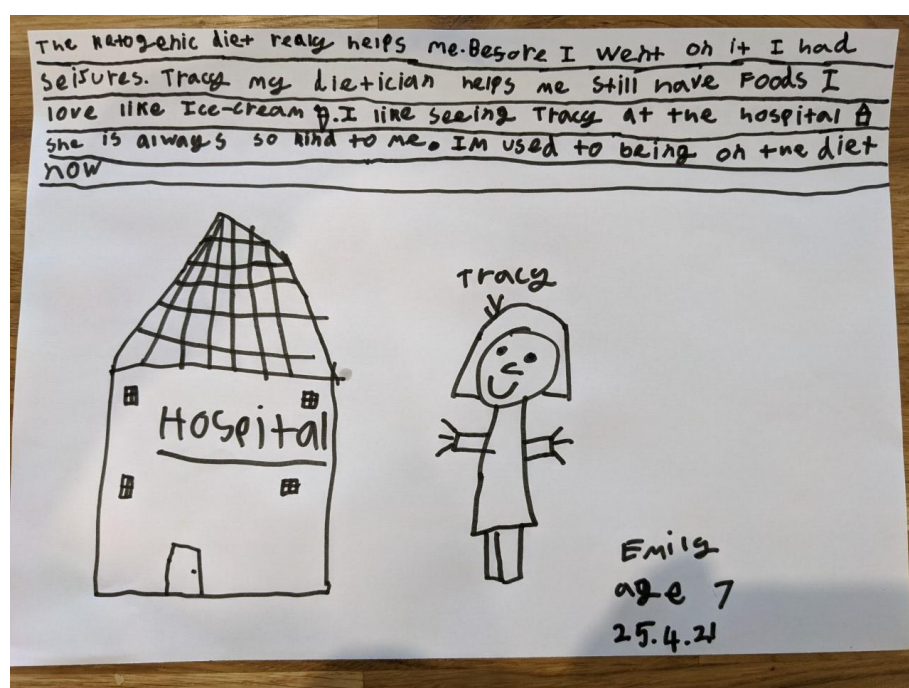
3.6 Ketogenic Diet Service

Over the last year, the Ketogenic Diet service has had a change in pace due to the COVID-19 pandemic which has resulted in a reduced quantity of referrals. Our dietitians have still been available to support families and our first port of call was to

write a letter to all families to allow them to be able to access shops more frequently if required and obtain more than 3 of any item that they require to manage the diet. At times there were limited supplies of eggs, double cream and butter in the shops due to the nation taking up baking but our families are resilient and made the best out of the situation!

Tracy continues to work in the permanent 0.5 WTE Ketogenic Diet Co-ordinator post providing valuable expert advice to support patients with complex epilepsy, who have failed two or more anti-epileptic medications or have glucose transporter type 1 deficiency. In the North of Scotland, there are a total of 22 patients currently on a ketogenic diet and there are five children waiting to discuss the possibility of starting. Tracy also supports 2 adult dietitians who each have 1 patient on the ketogenic diet that have transitioned to adult services. Advice was also provided to 2 families who are on hold at present due to having seizure control with recent treatments.

Emily and her mum, Sarah, wanted to share their story of their Ketogenic journey:



"When we first met Tracy we had little hope that the diet would work after so many failed medications. We were desperate and it felt like an impossible task to switch our food loving 5 year old onto a ketogenic diet. Tracy was so good at explaining it all to us and not overwhelming us so it felt like we could at least try it! She was always available for all my questions (of which there were many!) whilst we got the hang of things. We couldn't fault our experience and we are now over 2 years on the diet and nearly 2 years seizure free! Tracy is really approachable; I still have questions which she always responds to quickly. I know my daughter is in great hands with Tracy and our team."

Tracy continues to be passionate about upskilling dietitians to be able to deliver ketogenic diets to patients as close to their homes as possible. The annual Robert Gordon University lecture to dietetic students took place in February 2021 via zoom which meant no ketogenic brownies for the students to try! This is an important part of the dietetic role, to continue and educate future dietitians on the diet and this will continue in the forthcoming years.

Albena, a mum to Daniel who is on the Ketogenic diet and a dietitian studying at RGU has shared her amazing pictures:



The Ketogenic Diet Service held a virtual Ketogenic Diet Cookery session via Teams in 2020. Although this wasn't in person this year, it still provided families of children on the diet across Scotland a chance to meet up. Neil Palliser-Bosomworth (a Keto chef who works with both Matthew's Friend's, a charity which supports families on the Ketogenic Diet and Vitaflo), carried out the demonstration virtually. These days give families the opportunity to ask questions in an informal situation and we hope that we can host our usual face to face sessions in the near future.

Jenny, Beth's mum, wanted to let us know: "Beth and I massively appreciate the support from the ketogenic diet service. Some of these photos include recipes shared at Christmas time. It's great to get new ideas and try new things...especially now Beth is so into baking!"



Tracy aims to attend regular neurology network operational and steering group meetings, team meetings, as well as the Scottish Ketogenic Dietitians meetings to keep abreast of regional and national work streams and plans. NHS Grampian and NHS Tayside are centres included in the KIWE (Ketogenic Diet in Infants with Epilepsy) study; however, we have had no recruits at this time.

She is also part of the publicist team of the Ketogenic Dietitians Research Network. In August 2020, Tracy completed her Masters in Advancing Healthcare Practice and her project involved the review of Ketogenic Diet education in the NOS and the use of digital technology. Tracy had the opportunity to film a webinar for ketogenic dietitians on this topic. In February 2021 Tracy enrolled in a research degree with Robert Gordon University and will focus on qualitative research related to the ketogenic diet.

Rachel Arthur continues to support inpatients in Grampian and we are delighted that Aileen McKillop-Smith will be learning more about the Ketogenic Diet to add to our provision. Karen Lang continues to support the service in Tayside and has the capacity to increase her input which is welcome. Nikki Strachan continues to support our Highland families, although this post has no additional funding, it is a substantial help to the service. This small team of dietitians is essential to ensure adequate dietetic cover across the region for annual leave.

Our family from Orkney would like to share pictures of Logan, who is very hands on with cooking his ketogenic diet and has made a lovely film describing his experience for school:



Richard and Lorna wanted to let us know “they really valued feedback regarding his lipids and were able to control his hypertriglyceridaemia effectively by following dietetic advice. We're quite happy to be left to get on with managing Logan's diet independently because we know that we can access advice and support quickly by email and phone when required. The new EKM Mobile app has had a massive impact on our day to day lives and enables us to continuously recalculate Logan's menus in response to what we have in the fridge and cupboards, what the rest of the family is eating and what Logan decides he will and will not eat (which changes on daily basis!). Some of our relatives have downloaded the app meaning that (prior to the COVID pandemic) Logan was able to go and stay overnight with other members of the family for the first time in his life. This has been a huge relief for us as we now feel confident that if anything ever happens to us the rest of the family will be able to cope with Logan's diet without too much difficulty”.

Nikki and Aileen are both attending the virtual Ketocollege in May 2021 to increase their knowledge on Ketogenic Diet and network with dietitians, across the UK and International attendees. Tracy has also recorded her session for Ketocollege that will be streamed on ‘Ketogenic Diet and supplementation’.

Tracy Cameron, North of Scotland Ketogenic Diet Coordinator
Rachel Arthur, Dietitian, Aileen McKillop-Smith (Grampian)
Karen Lang (Tayside), Nikki Strachan (Highland)

3.7 Out of Hours Consultant Telephone Advice Rota

For a number of years there have been out of hours (OOH) on call neurology telephone advice services in Aberdeen and Dundee (consultant to consultant). Discussion took place during the year and an SBAR was written regarding setting up a regional OOH service in future which would be jointly staffed by consultants from Aberdeen and Dundee. A robust, safe and sustainable way is needed of providing Out of Hours telephone advice to the whole region and it was agreed that an operating procedure would be written and circulated for discussion and approval.

3.8 Patient Stories

Compliments for the team

Angus' Story

Angus was diagnosed with epilepsy at the age of 5 ten years ago. Over the years Angus' epilepsy has changed; he has a serious form of epilepsy which is difficult to control. He has generalised or tonic clonic seizures and focal seizures which can be very unpredictable. His mum said "He hates his epilepsy. He worries about what people think, and knows it affects him on a daily basis. It's a rollercoaster, however we try to give him as much of a normal life as possible".

Angus is a typical 14 year old boy. He loves rugby, both watching and playing it. That's his main passion. He plays the violin and loves singing, listening to music and watching films. He also enjoys playing on the Xbox with his younger brother Fergus who is 12. Fergus is great at working out when Angus is about to have a seizure and will let his parents know.

Angus and his family have known Pauline their Specialist Nurse for around five years. Angus' mum has said that Pauline is incredibly supportive and proactive in trying to help Angus. He has had endless tests over the last few years to help try and get to the bottom of what is the cause of his epilepsy.

Mum wrote "Pauline is always at the end of the phone when I need her to discuss anything". There have been episodes where Angus has a few seizures in a row and mum will text Pauline to ask her advice and when to administer emergency medication to stop the cluster of seizures. "It's so reassuring to know that she is there for us and that she always responds even when she is kayaking on a remote Scottish loch or climbing a mountain. It's nice to know I can let Pauline know and she will tell Angus' consultant, so they know the frequency of his seizures. I would really miss Pauline if we didn't have her. She is the nicest person, has a heart of gold and is so supportive of us as a family. I just think she's incredible and inspiring. Before we had Pauline's support, it was a disaster. It's so important to us as a family to have that support. We are fond of her as a family and I think she is fond of us too".

Pauline McEachen, Epilepsy Specialist Nurse



Sasha is a fantastic epilepsy nurse with my daughter Natasha. She has given me so much support with her medicines and her seizures as I didn't deal with them good, and she has helped me to build my confidence to deal with Natasha. She has given me support at meetings as well about Natasha's condition and she is a very lovely kind person to have.

**Sasha Peacock
Paediatric Epilepsy Specialist Nurse**

Chelsey's Thank You

Yes we were gutted not to see you to thank you for everything over the years; we would have been lost without you at times! We will never forget you and thank you for everything Jo. All the best, love from Chelsey and I ❤️❤️❤️'.



**Jo Campbell
Paediatric Epilepsy Specialist Nurse & NeSCANN Joint Clinical Lead**

4. New Developments

A first in Scotland for SMA gene therapy with Zolgensma

Two of our newly diagnosed SMA 1 network patients became the first Scottish recipients of gene therapy with Zolgensma on the NHS, with the first child being referred to Glasgow from the Dundee service and the second child from the Aberdeen service. Earlier this year both Dr Stephen and Dr Brink contributed and helped to devise the national Scottish SMA gene therapy pathway in discussion with Novartis, manufacturer of Zolgensma. Dr Stephen also participated as a national clinical expert for the SMC PACE meeting prior to the drug receiving approval for use in NHS Scotland on 8th March 2021. As Regional Neuromuscular Centres, both Dundee and Aberdeen clinicians were responsible for counselling of these newly diagnosed families, selecting the patients for this ground-breaking treatment, instituting pre-treatment tests including AAV9 antibody testing, liaising with the national Infusion Centre colleagues (Glasgow) for planning and administering the treatment, as well as participating in the post-treatment follow-up monitoring. The logistics of organising and delivering this new treatment (that is at present the most expensive drug ever marketed in the world) was a learning curve for both clinicians and families.

In Grampian, my patient was also unique as being the youngest patient in Europe to date, to receive the treatment at only 20 days of age, with a very timely diagnosis having been confirmed on day 13 of life. This is as good as being picked up via a newborn screening programme, for which a case is now being made in the UK. It is a privilege to be able to have first-hand experience of this type of treatment, and to follow-up this patient long-term. Grampian SMA patients are also enrolled onto the SMA REACH database to ensure that we contribute to nationally recorded information, and our local standards of care are comparable to larger neuromuscular centres in the UK.

Read what my patient's parents had to say [Because you're worth it: Parents' joy as Scots babies become first in UK to get £1.8m life-transforming, hope-giving treatment - The Sunday Post](#)



**Dr Elma Stephen
Consultant Paediatric Neurologist**

4.1 Clinical Pathways

4.1.1 VNS (Vagus Nerve Stimulation) pathway

Due to adult neurosurgery retirements at Ninewells and new neurosurgical staff starting at the start of the pandemic it had not been possible to have discussions with the new staff to discuss service provision for paediatric patients and agree a new pathway. In the interim, to allow timely intervention, the NeSCANN membership agreed that referral of these patients should be made to Edinburgh via the SPESS (Scottish Paediatric Epilepsy Surgery Service) pathway. In due course, Miss Anna Solth is going to take the lead for paediatric neurosurgery at Ninewells and will help to develop pathways and guidelines with network staff. In future Mr David Bennett has agreed to treat network patients but there are still constraints in Ninewells theatres due to Covid-19 pathways.

4.1.2 Management of Spina Bifida pathway/Foetal Surgery pathway

Clear pathways/guidelines on these pathways will be developed in collaboration with surgical colleagues over the coming year.

4.1.3 CBD (Cannabidiol) Network Guideline

Following the Government agreement to prescribe cannabidiol for a small number of patients that have complex epilepsies. NICE produced guidance but it has been agreed that a regional approach will be required and a concise network protocol was developed. The starting criteria for two licensed indications are for children with Dravet syndrome or Lennox-Gastaut Syndrome. Children should have failed two anticonvulsants and Cannabidiol needs to be used with clobazam. If patients do not fit the criteria, such cases can be discussed at the Refractory Epilepsy Clinical Advisory Service of the BPNA for consideration to prescribe cannabidiol out with its license indications.

4.2 New Video-telemetry (VTEM) system in RACH

We were successful in gaining funding for an in-patient telemetry service in RACH. This equipment was fully commissioned recently and opened with the first 2 patients already having had this investigation locally as part of the work-up for potential epilepsy surgery. Long term video-EEG monitoring has several uses, both for event monitoring, and as a mandatory investigation for assessing candidates for epilepsy surgery. This facility, located in RACH HDU, will allow for timely and locally accessible assessments for Grampian patients initially, as well as facilitating a potentially prolonged hospital stay closer to their homes. A training package was devised, and separate training sessions were delivered for medical staff and HDU staff prior to the equipment being first used.

A new VTEM patient pathway including new RACH VTEM admission paperwork which is a 'one-stop-shop' medical record for use throughout the episode of care, including usage for the reporting of the telemetry, is now in place. The neurology team has a pre-admission meeting with the ARI neurophysiology team to discuss an individualized plan for each patient being admitted for this investigation. The HDU monitoring set-up conforms to (and arguably exceeds) the standards of care for video-telemetry units recommended by published expert consensus guidelines for UK telemetry units. Consultant desktop access to these live recordings for both Dr

Stephen and Dr Serino allows for timely advice for immediate patient care and some technical aspects of the recording. The enthusiastic contribution of the HDU staff and neurophysiology staff to the success of this new service development has been welcome, and we have been pleased to recently nominate these teams for the Grampian Staff Orange Awards (we hope they win!).

**Dr Elma Stephen
Consultant Paediatric Neurologist**



New updated VTEM equipment has also now been fully installed in Dundee.

4.3 vCreate – information sharing system

The video sharing service – called vCreate (Neuro) – has been independently assessed by Information Governance teams in UK NHS Trusts and is a new national platform designed specifically for Emergency Departments. It allows registered patients and carers to share smart phone recorded videos of potential seizures with clinicians through a secure system. This has been piloted in Scotland and is being used quite successfully by clinicians and families.

5. Training & Education

NeSCANN is committed to ensuring a highly skilled and trained workforce. Professional support continues to be regularly available by way of formal and informal teaching or learning opportunities and case discussions.

Monthly multi-disciplinary meetings take place in the 3 main centres providing teaching and education sessions, i.e.

- “Brainwave” (Ninewells) – available across the region by Teams
- “Neurology Open Day” (Royal Aberdeen Children’s Hospital)
- Raigmore Hospital, Inverness – lunchtime sessions alongside the visiting Consultant Neurologist clinics. In addition, 2 MDT days now take place at Raigmore twice per year covering topics such as continuing professional development, EEG, neurophysiology and neuroradiology reviews.

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

Due to the new video technologies this year, there have been several free courses provided through the BPNA which have been of great benefit to professionals. These have been more accessible to all staff and have reduced travel time and costs. Similarly a number of national meetings have also been attended virtually by network clinicians, e.g.

- BPNA annual conference, , January 2021
- Scottish Paediatric Neurology Group (SPNG)
- Scottish Paediatric Epilepsy Surgery Service (SPESS)
- SPEN Members' and Research days
- SPEN special interest group meetings
- Scottish Muscle Network (SMN)
- RCPCH annual conference

Medical Training posts

There are a number of opportunities for post-graduate training in the North including SPIN modules in epilepsy and neurodisability. Discussions are ongoing with regard to a joint Neurology GRID training post between Dundee/Aberdeen with Edinburgh/Glasgow in the future. These pan-Scotland programmes utilising the specialisms to be found in each region are likely to evolve in the coming years as there is a recognition of the need to 'grow our own' for a sustainable future. The recent amalgamation of paediatric training into a single deanery will undoubtedly be helpful in this regard.

5.1 Tayside educational highlights

Postgraduate grand round teaching in Tayside has now been restructured to follow a designated themed approach. We had the opportunity to deliver the first neurology teaching programme in February/March 2021 covering topics such as Demyelinating Disorders in Childhood, An Approach to headache, Status Epilepticus and Paediatric Neurosurgical Emergencies. Trainees have been very positive about this structured approach and have given very positive feedback. We will continue to build on this annually to ensure the curriculum and important topics in neurology are covered over a 2-3 year cycle going forward.

The use of Teams has broadened participation in our Brainwave meetings throughout Tayside and the North. In particular we have been privileged to have some excellent teaching delivered by our Locum Consultant Neurologist, Dr Paul Eunson, who has brought a lifetime of experience and practical know how to these meetings. His knowledge and experience around advanced tone management, in particular, and the use of Baclofen pumps has been especially helpful.

5.2 Grampian educational highlights

1. The Grampian paediatric neurology team delivered the first pan-RACH Child Neurology CME and M & M session on 19/05/2021, with a selection of case presentations, guideline updates, audits and QI projects discussed with a wider hospital audience.

2. Dr Stephen and neonatal colleagues completed the Neonatal Seizures Guideline which is now available on the NHSG intranet for clinicians to access

5.3 Epilepsy Specialist Nurse training for emergency medication administration

Jo Campbell and Ena Cromar facilitated generic training sessions using Teams for schools and nurseries which took a huge amount of work but this is now working well.

Similar generic training sessions have been carried out by Pauline McEachen and Sasha Peacock in Tayside and Kirsteen Mackintosh and Kelly McBeath in Highland

Jo had also collaborated with an independent nurse consultant who was contracted by the medication supplier and given funds to develop an animated video, demonstrating the administration of the emergency medication. It is the intention that this will be ratified by SPEN. The ultimate ambition is to have a complete Epilepsy Awareness and Emergency Medication training package hosted on the TURAS platform so that staff can have access to this nationally. Jo Campbell has started discussions with Caroline Mearns and Dr Jean Cowie (NES) in regards to this initiative.

5.4 National Competencies for Paediatric Epilepsy Specialist Nurses

Jo Campbell and Kirsteen Mackintosh have been actively involved in the national working group developing a competency framework for Paediatric Epilepsy Specialist Nurses. This is in collaboration with ESNA (Epilepsy Specialist Nurses Association) and RCN (Royal College of Nursing).

6. Research & Audit

Grampian

Research: recruitment continued to the following studies once some research related patient restrictions were eased:

1. Epilepsy studies: REGAIN, BIOJUME, KIWE
2. Neuromuscular: SMA-REACH, Northstar

Audits presented at RACH Neurology CME:

1. DMD Care pathway audit presented by Dr Aditi Majethia, ST5
2. Melatonin Sedation for MRI scans: joint QI project with radiology presented by Kim Houg Lim ST2 Radiology, Drs Shoab Khan and Dr Deniz Morgan

Tayside

Some studies were temporarily suspended due to COVID hampering recruitment. We have continued to participate in the REGAIN, BIOJUME and KIWI studies with set up in process for the PARROT and SMA REACH studies progressing.

7. Key Challenges

The need for numbers of clinics is reviewed regularly across the network with local service managers. However there has always been a lack of data available on network patients to enable network staff to plan services with a greater degree of accuracy. Unfortunately the Scottish Government decided that Scotland would not take part in Round 3 of the national Epilepsy 12 audit. This was very disappointing and we await further information on the developments of a Scottish audit system. Dr Joe Symonds and Dr Jay Shetty have been involved from SPEN looking at our national requirements that will be met by a Scottish system.

- **Recruitment to vacant posts**

The retirement of Professor Martin Kirkpatrick has left a significant gap in network and service matters at Ninewells. We have however been able to appoint two very able locums in the interim. Recruitment of child neurologists remains very challenging across the UK. There are numerous vacant posts and insufficient GRID trainees completing or being recruited to training. Brexit and COVID have also significantly hampered attempts to recruit very suitably qualified neurologists from abroad.

- **Attracting trainees to consider child neurology as a speciality and facilitating training opportunities**

The enthusiasm of local teams, working with Training Programme Directors and training leads across Scotland to ensure undergraduate and junior postgraduate trainees have opportunities to experience child neurology will be essential in ensuring we can train and grow our own sustainable child neurology services for the future. This will require demystifying the speciality and creating opportunities for undergraduate and post graduate engagement throughout the North.

8. Looking Ahead

This year has been like no other any of us have ever experienced. Who would have thought one year on from its onset that we are still under restrictions in our daily lives? Our staff have been amazing and have worked extremely hard to deliver the best care to our network patients in these most difficult of circumstances.

The learning of new video technologies has been embraced by all staff meaning that neurology and epilepsy patients and their families were still able to be seen in clinic appointments across the North with face-to-face appointments also being delivered when appropriate.

As vaccinations numbers continue to increase there is hope that life will slowly return to some sort of normality. Hospital services are starting to look more normal with more patients being seen face-to-face in clinics across the region. However given the population has not been mixing for some months, this new phase will no doubt bring new challenges in health services.

We will be updating the network work plan to highlight our priorities for the coming year.

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

Network Management	POST	Comment
Jo Campbell	Paediatric Epilepsy Specialist Nurse	Joint NeSCANN Clinical Lead
Dr Alice Jollands	Consultant Paediatric Neurologist	Joint NeSCANN Clinical Lead
Dr Elma Stephen	Consultant Paediatric Neurologist	Joint NeSCANN Clinical Lead
Carolyn Duncan	Child Health Network Manager	Also Network Manager for NoS Gastroenterology and Respiratory networks

NAME	POST	
ABERDEEN		
Dr Elma Stephen	Consultant Paediatric Neurologist	
Dr Shoaib Khan	Consultant Paediatrician with a special interest in Epilepsy	
Dr Domenic Serino	Locum Consultant Paediatric Neurologist	
Diane Honeyman	Medical Secretary	
Jo Campbell	Paediatric Epilepsy Specialist Nurse	1 wte
Ena Cromar	Paediatric Epilepsy Specialist Nurse	Retired March 2021
Dr Bruce Downey	Neuropsychologist	
Tracy Cameron	Ketogenic Diet Co-ordinator	0.5 wte
Rachel Arthur	Dietitian	
Rosie McKee/Sue-Ann Grant	Speech & Language Therapist	
Jane Tewnion	Neuromuscular Physiotherapist	9 hours
Physiological Technician		0.3 wte funding (purchasing services)
DUNDEE		
Dr Alice Jollands	Consultant Paediatric Neurologist	
Dr Philip Brink	Consultant Paediatric Neurologist	Also works in Highland
Dr Linda Clerihew	Consultant Paediatrician	
Dr Paul Eunson	Locum Consultant Paediatric Neurologist	Part-time
Sheila Kerr	Medical Secretary	
Pauline McEachen	Paediatric Epilepsy Specialist Nurse	
Sasha Peacock	Paediatric Epilepsy Specialist Nurse	Started January 2019
Dr Aileen McCafferty	Neuropsychologist	
Jo Clough	Physiotherapist – Intrathecal Baclofen	
Nicola Whatley	Physiotherapist	
Karen Lang	Dietitian	
INVERNESS		
Dr Alan Webb	Consultant Paediatrician with a Special Interest in Epilepsy	5 PAs for epilepsy service Moray/Highland
Rebecca Mayes/ Alison Bown	Medical Secretary	
Dr Linda MacLellan	Consultant Paediatrician	Retired March 2021
Dr Gavin Cobb	Consultant Paediatrician	Responsibility for neuromuscular
Dr Lesley Henderson	Consultant Paediatrician	Responsibility for tone management
Kelly McBeath	Paediatric Epilepsy Specialist Nurse	part-time
Kirsteen Mackintosh	Paediatric Epilepsy Specialist Nurse	part-time
Julie Burslem	Regional Neuromuscular Physiotherapist & Care Advisor	13 hrs (based in Highland)
Nikki Strachan	Dietitian	
Yvonne MacLean	Dietitian - Wick	
Dr Tracy McGlynn	Psychologist	
SHETLAND		
Dr Susan Bowie	GP with a Special Interest	Based at Hillswick Health Centre
ORKNEY		
Penny Martin	Physiotherapist	

**North Scotland Child & Adolescent Neurology Network
(NeSCANN) Work Plan 2020-21**

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

Objectives	Linked Dimensions of Quality	Outcome	Tasks	Timescales	Lead Professionals	Progress at March 2021
Develop information on network, pathways & protocols for secondary and primary care staff as well as patients and families	Patient-centred, Efficient, Equitable	Enhances clinician knowledge of service and of disease information	<ul style="list-style-type: none"> Develop and review already published information and pathways that could be regarded as network standards Identify local needs in addition to network needs Develop network VNS checklist 	2020-2021	A Jollands E Stephen C Duncan J Campbell	Work in progress. VNS checklist to be finalised. Amber
Develop Key Performance Indicators in epilepsy care with reference to Epilepsy 12 national audit group	Patient-centred, Efficient, Equitable	To measure and have ability to benchmark network performance in children's national epilepsy care	<ul style="list-style-type: none"> Following regional participation in the Epilepsy 12 national audit and a future Scottish audit system be involved in discussions on formulation of KPIs for epilepsy care 	2020-2021	P Brink A Jollands E Stephen	Information on KPIs from Epilepsy 12 awaited. To date Scotland not involved in Round 3 of Epilepsy 12 as Scottish Government to set up their own epilepsy audit system. Amber

Objectives	Linked Dimensions of Quality	Outcome	Tasks	Timescales	Lead Professionals	Progress at March 2021
Develop network electronic EEG access in collaboration with Health Boards' Physiology services	Safe, Equitable, Efficient	Set up remote electronic access for clinicians to patient EEGs across the network	<ul style="list-style-type: none"> Be involved in discussions locally and ensure the implementation of vCreate EEG IT system in each Health Board 	2020-21	D Serino E Stephen A Jollands P Brink A Webb	Implementation of vCreate commenced. Amber
Work with adult clinicians in the North of Scotland to increase number of Transition clinics	Patient-centred, Efficient, Equitable	Improved communication links with adult services for better transition from paediatrics to adult services for network patients	<ul style="list-style-type: none"> Set up individual Health Board meetings with adult medical staff and specialist nurses Review current transition clinic provision and jointly develop new clinics where required 	2020-21	K Mackintosh A Webb	Tayside and Grampian transition clinics in place. Dr Webb liaising with Raigmore neurologists. Dr Webb doing twice yearly joint clinic with Dr G McKay (ARI neurologist) at Dr Gray's Elgin. Green
Work with Roald Dahl Marvellous Medicine Charity regarding 2 year funding for a NoS Epilepsy Nurse Consultant	Efficient, Equitable	Post agreed and in place for 5 years to develop a regional Epilepsy Specialist Nurse Consultant role	<ul style="list-style-type: none"> Liaise with Sophie Dwilinski at Roald Dahl to discuss support for a post in the North of Scotland Liaise with North of Scotland Planning Group to develop a business case and to facilitate discussions with Health Boards to provide 3 years of funding once 2 years from Roald Dahl ceases 	2017-21	J Campbell C Duncan A Jollands E Stephen	Discussion took place with Sophie Dwilinski who was supportive of the post but indicated the charity is now focusing on transition as their priority and so this post would not fit with their criteria currently. Red
Set up a regional Out of Hours Consultant Telephone Advice Service	Safe, Efficient, Equitable	A rota for a regional advice service would ensure an equitable service across the region (local rotas currently)	<ul style="list-style-type: none"> Write an SBAR to highlight the issues Discuss with local management teams and network colleagues to gain agreement for new system Write a Standard Operating Procedure (SOP) 	2020-22	E Stephen A Jollands P Brink D Serino	SBAR written and discussed. Draft SOP to be written – hope to finalise summer 2021 depending on sufficient staff in post. Amber

