

Children's Hospitals Network



Newsletter *July 2016*

issue 2

Introduction

Since our 1st Newsletter in April the CHN has continued to move forward with the **implementation of the Operational Delivery Networks for Paediatric Neurosciences, Critical Care** and most recently **Cardiac**.

You can contact us on **oschn@ouh.nhs.uk** or check out our website for more details **www.oschn.nhs.uk**

inside:

| | |
|--|----|
| Improving Communication | 2 |
| Children's Neurosciences Network (ODN) | 3 |
| Children's Critical Care Network (ODN) | 4 |
| Children's Rehabilitation Network | 6 |
| Children's Cardiac Network (ODN) | 7 |
| Other Network Developments | 8 |
| Children's Orthopaedic Network | 9 |
| Patient focus | 10 |
| Dates for your diary | 12 |

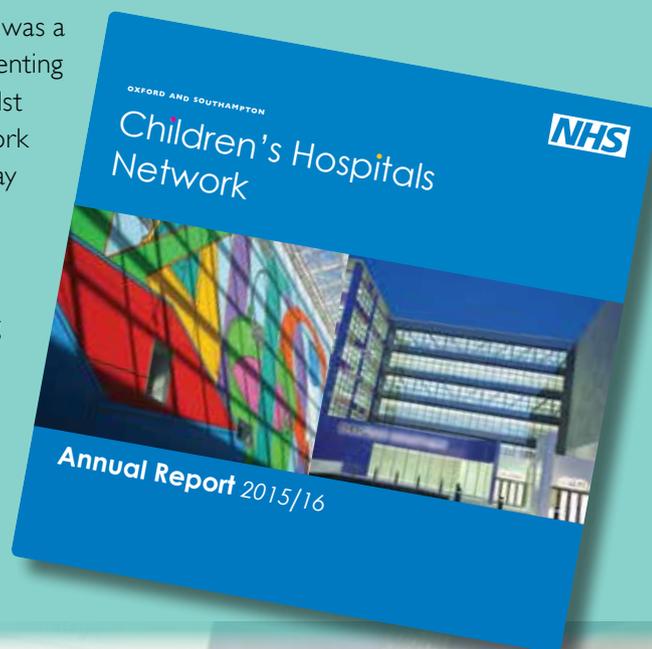
The first Network of its kind...

Improving Communication



Alison Sims
Associate Director
Children's Hospitals
Network

“Annual Report published – 2015 was a very exciting year for the CHN: implementing the ODNs for some of our services whilst new specialties wished to join the network or replicate our model of working. In May we published our 3rd Annual Report. The report reflects on developments that have taken place during 2015 and focusses on the priorities for the coming year. The report can be downloaded in pdf format from our website <http://www.oschn.nhs.uk/news/annual-report-2015-2016/> or alternatively if you would like hard copies, please get in touch via the website!”.



Operational Delivery Network (ODN) Update

The **National NHS Commissioning Board** introduced ODNs in order to focus on coordinating patient pathways between providers over a wide area, ensuring access to specialist support and expertise. Since then a number of ODNs have been established across England. As you will have read previously the CHN currently hosts three paediatric ODNs for Neurosciences, Critical Care and Cardiac across the Thames Valley & Wessex regions.

A National Review is currently taking place which will determine the way forward for ODNs and will set out how they will be funded and managed in the future. We hope that we will have received enough information before the next newsletter so that we keep you informed, but in the meantime check the CHN website for updates.

Children's Neurosciences (ODN)



Heather Deeley
(ODN) Manager
Neurosciences
Thames Valley & Wessex



Aabir Chakraborty
Clinical Lead
Neurosciences (ODN)
Thames Valley & Wessex

1st PAEDIATRIC NEUROSCIENCES MULTI-PROFESSIONAL CLINICAL DAY A SUCCESS!

On the 3rd May 2016, 45 neurosciences professionals from across Thames Valley and Wessex met for the 1st Paediatric Neurosciences Clinical Day. This was the first opportunity for clinicians, nurses, allied health professionals and managers from across the Thames Valley & Wessex ODN and further afield to network and share ideas to improve the quality and experience of care for neurosciences families within our region and beyond. The day was well received and feedback suggested that delegates wanted further opportunities to interact and network. Future communications will be managed via the Basecamp portal and all members will receive an invitation to join. We will be planning the next event shortly and would welcome input of subjects that you would like to see included in the next programme.



Discussing how to improve the support of neurosciences families.

Welcome to Nadine Duffin, Project Manager Paediatric MRI – We are very excited to be welcoming Nadine Duffin to the ODN team for the next year in a part-time capacity. Since graduating as a Radiographer in 2007, Nadine has developed her skill set through roles in paediatric radiology, radiation quality and governance (RQAG) at Southampton as well as working for NIHR Thames Valley CLRN as a research radiographer. Most recently she has completed her MSc and this role will support her development further.

When asked what she would like to achieve in this role, Nadine replied, "I am looking forward to joining the ODN and undertaking the project management role for Paediatric MRI, as I believe this an important project role with the increasing number of MRI scans on a year on year basis, and whilst I spent time in MRI for the GA MRI list once a week, I could see the frustration of the superintendent radiographer at Southampton trying to fit urgent GA MRI scans in a timely fashion whilst still trying to maintain the routine non-urgent service, and hear the clinicians and parents frustrations. Over the next 12 months, I aim to find out across the network, what the 'blue sky' image of Paediatric MRI service provision is from the clinicians and service users. To identify bottlenecks within the current service provision and look at national and international service provision to identify areas of good practice and translate this is to proposals to improve our access to Paediatric MRI across the network. It's going to be a big project but one I can't wait to sink my teeth into."



Nadine Duffin
Project Manager
Paediatric MRI

Children's Critical Care (ODN)



Carolyn Cairns
Manager
Critical Care (ODN)
Thames Valley & Wessex

NEW DEVELOPMENTS – The Paediatric Critical Care ODN has just agreed an update to the inter-hospital transfer form which will make transfers of patients by hospital teams (non-SORT transfers) consistent across the region. This was rolled out during May and will be monitored for feedback.

The Thames Valley & Wessex Sepsis tool is also live now which is giving staff the opportunity to assess consistently for risk of sepsis in patients and escalate care to specialists as necessary. The tool was audited a few months ago before it was finalised and was proven to be very effective at identifying possible sepsis.



Mike Linney
Clinical Lead
Critical Care (ODN)
Thames Valley & Wessex

COLLABORATION – The ODN has been busy meeting other Paediatric Critical Care ODN leads around the country, and we're also working hard to get to know informal paediatric critical care networks around us. We have shared our pathways and clinical tools with them and have also received some of their developed pathways to review and potentially implement.

In mid-April we were invited to the West Midlands meeting which was very useful and it was great to make contact with such an enthusiastic team. We look forward to remaining in close contact with other teams all working on paediatric critical care so that we can share our learning and work together to make positive improvements.

FIRST NETWORK JOINT CLINICAL FORUM

16TH JUNE – around 60 critical care professionals from across Thames Valley & Wessex will meet for the 1st Joint Paediatric Critical Care Clinical Forum. The day will be the first ODN opportunity for all team members across the region to come together to network and share learning. The day is due to be a busy one, with an opportunity for all hospitals in Thames Valley & Wessex to contribute to the way we move forwards together.

First Network Board Meeting – The first Paediatric Critical Care ODN Board Meeting is due to take place on 4th July 2016. This will mark the official start of the executive board in overseeing the work of the ODN and the final workplan for 16/17 should follow in the next few months.

EDUCATION – The 5th May education day at Salisbury went extremely well with good attendance and positive feedback. Watch out on the network website for future dates.

Children's Critical Care (ODN) (continued)

PROJECTS – The ODN team is currently focusing on a couple of high dependency (HDU) projects as this is an important area of paediatric critical care which we would like to review in our region. We have asked all of our hospitals to complete a brief one-off scoping exercise to identify how they currently care for certain high dependency patients and we will then look at any variation in pathways and work to ensure that hospitals are supported to make improvements, if necessary. Knowing how each hospital cares for these patients will also help us to identify the best way of doing things, and we can then spread this throughout our hospitals.

Data for HDU patients is the second project. We would like to begin to collect routine data on HDU patients so that we understand how many HDU patients there are in our area at any given time, and how they are being cared for. This data will help to build a detailed picture of our services, and again, will help us identify areas we want to work on to make improvements.



Children's Rehabilitation Network



Sophie Goddard
Network Project Manager,
Rehabilitation

We were sorry to say goodbye to Sophie Goddard recently when her Management Training placement came to an end. Sophie has made an excellent start in moving the Rehabilitation Network forward and you can read her feedback below. Much of the remit for this network focusses on Neuro Rehabilitation which will be supported by Heather Deeley going forward.

Sadly, my time on the NHS Management Training Scheme and subsequently my placement with the CHN has come to an end. I have thoroughly enjoyed my time working on the Rehabilitation Network; have met some fantastic people and take away invaluable learning. The very nature of Networks mean they often take years to mature and so helping the clinical team to develop the Network from scratch has had its challenges. Every organisation runs its services very differently and these services often align to very diverse Trust objectives. However, services have particular areas of expertise and research, meaning that much can be learnt from each. I hope that I have assisted in laying the foundations of what will be a successful partnership between the two organisations and across the Thames Valley & Wessex region in the future.

Working for the CHN has fuelled my new passion for Women's and Children's services and for that reason I have been inspired to remain working in paediatrics, post-scheme. This is for a number of reasons; I was struck by the dedication and care that the Network clinicians and managers exhibit to ensure children and young people receive the best care possible and I have enjoyed learning and understanding about specialist service delivery, perhaps because the conditions presented are relatively rare and unique. As the project with the CHN has been strategic, I have chosen to gain further insight of operational management after the scheme. I have been fortunate to secure myself a position as Service Manager for Paediatrics (critical care, neurology, respiratory, endocrinology and diabetes) at the Royal London Hospital (Bart's Health). I am extremely pleased to be starting my career in an area within which I love, off the back of a great final placement with the CHN.

NEURO-REHABILITATION NETWORKING

MAKING GREAT STRIDES – The Neuro-Rehabilitation services at both Oxford and Southampton have recruited their teams and are seeing patients using their new care models. The initial patient feedback is excellent and all are working together to share best practice and consistently collect data to allow benchmarking. Although in their infancy the future looks bright for in-patient neuro-rehabilitation. An outpatient model is also being developed across the region that will support further improvements for the care of children requiring neuro-rehabilitation.

On 7th July 2016 both teams will be hosting a research day specifically focussed on the development of research into paediatric neuro-rehabilitation. This is a great example of how a network we can work better together and hopefully improve care for children of not only now, but the future too. A full update on the day will be given in the next newsletter.

Children's Cardiac Network (ODN)



Alison Sims
Interim Cardiac
Network Manager

Cardiac is currently undergoing ODN implementation. Over the years Oxford and Southampton trusts have worked closely to ensure that this specialised service is provided to patients across the Thames Valley & Wessex Regions.

CLINICAL LEAD – we recently advertised the position of ODN Clinical Lead and are pleased to announce that **Kevin Roman**, Consultant Cardiologist, UHS has been successful in this post. Kevin has been heavily involved in the on-going National Cardiac review and is keen to develop the network.



Kevin Roman
Clinical Lead, Cardiac ODN
Thames Valley & Wessex

NEW CONGENITAL HEART REVIEW – The national review is coming to fruition. NHS England are working with all NHS providers of Congenital Heart services to consider how they might collaborate to meet nationally agreed standards. The Oxford and Southampton network have submitted proposals in line with other providers within the national timeline. The NHSE review team have scheduled national meetings between June 2016 and March 2017 which will provide further opportunities to discuss specific themes and to consider wider Networking.

COLLABORATION – we continue to liaise with other Cardiac Networks with a view to sharing expertise and best practice and do not rule out further networking in the future. We are keen to develop and continue to provide excellent standards for the patients and families across the Thames Valley & Wessex regions.

NATIONAL INSTITUTE FOR CARDIOVASCULAR OUTCOMES RESEARCH (NICOR) have recently published their 2012-2015 report. The findings are based on data submitted by 34 hospitals including all 14 specialist Paediatric centers. This covers all NHS and private Paediatric and congenital heart disease procedures undertaken at centers in the UK and Republic of Ireland. Analyses are based on 30,929 Paediatric and congenital heart surgery and interventions undertaken between April 1st 2012 and March 31st 2015. We are pleased to report that we fared very well in the report, which demonstrates the high quality outcomes that have been continually achieved by our teams.

The report can be viewed via the link below:

<https://nicor4.nicor.org.uk/nicorwelcome.nsf/0/700DBE5FA3731C4680257F7D002FC07B?OpenDocument>

Other Network Developments



Katie King
CHN Transition
Project Lead

TRANSITION –our project to implement the Ready, Steady, Go (RSG) transition model continues to gain speed.

Southampton Trust has led the way on Transition for a number of years now demonstrating that RSG is a successful model. This has enabled us to improve parity across the Thames Valley & Wessex regions in a number of ways:

At OUH we have implemented a Transition Working Group which has been well attended by numerous paediatric and adult services. The main objectives of the group are:

- To implement a Transition policy for the OUH, based on the Ready Steady Go Transition model (and in line with UHS)
- To discuss further streams of Transition which will benefit Children and Young people who are involved in our services
- To agree outcome measures that will help us to monitor and continuously improve our Transition services
- To ensure joined up working across the Thames Valley & Wessex regions ensuring parity across all of our services



Polly Schofield
Lead Nurse for Transition
Royal Berkshire NHS
Foundation Trust

Katie King was integral in the implementation of this work stream and we were sad to say goodbye when she commenced maternity leave at the end of 2015. Following this we were delighted to hear that the Thames Valley Strategic Clinical Network (TVSCN) agreed to backfill this post for a further 15 months. This will enable us to implement a sustainable Transition programme and gain parity across the regions.

Polly Schofield, is Lead Nurse for Transition at the Royal Berkshire NHS Foundation Trust and has led a very successful process including a pilot project involving more than 100 patients/ parents. Polly is working with us to help progress our Transition programme and will also be on-hand to provide any further training or questions that teams may have.

We plan to join up all streams of Transition across the Thames Valley & Wessex regions during the coming year to ensure that we can continue to develop this important aspect of patient care.

Keep in touch with our project by checking the CHN website link at <http://www.oschn.nhs.uk/our-services/transitional-care/>

Did you know? – The **National Institute for Health and Care Excellence** (NICE) has recently published guidelines for Transition from children's to adults' services for young people using health or social care services

The guidelines can be viewed via the link: <https://www.nice.org.uk/guidance/ng43>

Other Network Developments (continued)

Children's Orthopaedic Network



SURGEONS PROVIDE VITAL TRAINING FOR AFRICAN CHILDREN

Surgeons from the Nuffield Orthopaedic Centre (NOC) returned to Ethiopia to provide training for local clinicians to treat debilitating childhood conditions.

They visited Black Lion Hospital and CURE Ethiopia Children's Hospital in Addis Ababa in March for a four-day children's orthopaedic surgery course. The NOC surgeons have been providing training on the continent for the last three years and were joined by clinicians from hospitals in Bristol, Sheffield and Toronto.

Care for children's disability is limited in Ethiopia with about 70 orthopaedic surgeons covering a population of 96 million people. The course covered common conditions such as clubfoot, neglected injuries, cerebral palsy, and hip dysplasia through interactive lectures and clinical case reviews.

The workshops included gait analysis, deformity correction, demonstration of surgical approaches, examination of patients and Ponseti method to manage clubfeet.

Children with clubfeet are born with their feet pointing down and inwards and with the soles of the feet backwards. The Ponseti method involves gently manipulating the feet to a better position and putting them in a cast.

Consultant Orthopaedic Surgeon at the NOC, Mr Tim Theologis, said: "Both the trainees and faculty enjoyed the training week immensely, particularly the opportunity to discuss challenging cases with experienced colleagues from around the world, and to pass on practical skills, tips and tricks through the hands-on workshops."

Over the past three years, 11 NOC surgeons have volunteered as instructors for four surgical training courses in Addis Ababa, training around 120 orthopaedic residents.

This is part of the COSECSA Oxford Orthopaedic Link programme, linking the University of Oxford's Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS) with the College of Surgeons of East, Central and Southern Africa (COSECSA).

The programme is funded by the UK Department for International Development (Health Partnership Scheme) and directed by NDORMS' Professor Chris Lavy and Professor Hemant Pandit.

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Patient Focus

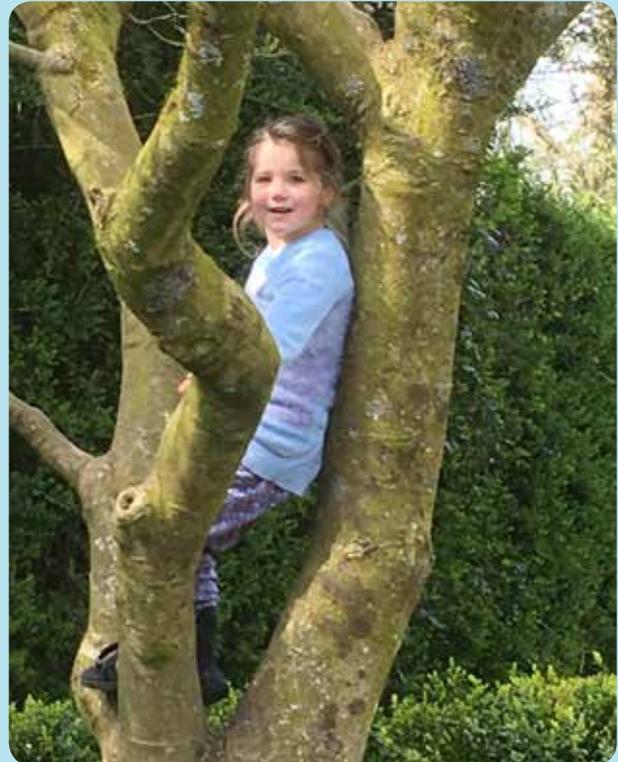
Alice Stott

On 18th July 2010, baby Alice was welcomed into the world by her parents, Ed and Sam Stott. The first born, she developed as any baby was expected to and the new family spent time getting to know each other.

In the Summer of 2011 Alice started to experience 'jerks' which were thought to be as a result of a fever but quickly these became more regular. As a result she was referred to Basingstoke where she was diagnosed with benign myoclonic epilepsy. These initial 'jerks' weren't regular and seemed to be well managed with medication. At one point there was a period of 6 months where she was asymptomatic for six months and Ed and Sam began to believe that there wasn't so much to worry about. The team at Basingstoke set up an open access arrangement for Alice where if there was anything wrong they could call or email or if necessary, take Alice straight into the hospital. A series of genetic tests were also undertaken due to a history of paternal epilepsy, this was ruled out.

In 2012, Ed and Sam welcomed Alice's brother, James, to the world. What should have been a happy time for the family was marred by the constant worry about Alice's condition.

In October 2013 Alice experienced her first whole body tremors, otherwise known as seizures. These would come in clusters and last up to 30 seconds at a time. At one point she experienced over 100 tremors in a period of 2 hours. This was distressing and frightening for the family and Alice was able to predict the seizures, saying, "it's doing it". Unfortunately the medication was no longer controlling the seizures and Alice was admitted via ambulance to Charlie's Day Unit at Basingstoke hospital 8 times in 6 weeks as a result of her seizures. This would sometimes be a difficult process as Alice's post-seizure medication would make her "bounce off the walls" and some ambulance crews were reluctant to transport her as they did not understand why an ambulance transfer was warranted despite the fact that she held a



statement, now known as an Education, Health and Care Plan.

At this point referral to the specialist epilepsy team at Southampton was the only sensible option. The consultant immediately made it clear that she was looking to solve the problem of Alice's epilepsy rather than to manage it and arranged an array of tests. Having initially been told that it was likely that Alice would grow out of her epilepsy, this was a reality check for Ed and Sam and they realised her condition may have a long-term impact on the quality of her life and also of the family.

Over a period of time, Alice was tried on a number of different drugs with varying degrees of success, but it was found that she had developed a form of drug resistant epilepsy which meant that as her body became used to the drug, it would stop being as effective and the seizures would no longer be controlled. Throughout all of the meetings with the team, it was a very collaborative approach which involved the consultant, the epilepsy nurse specialist, Alice and Ed and Sam.

Alice Stott (continued)

In September 2014 Alice started school. A significant seizure on her first day was not quite the plan and she was admitted to hospital. This was upsetting for all involved and Alice was only able to complete half-days including a nap due to her medication at first. At this point, Sam decided not to return to her work as a lawyer as she needed to be able to support Alice at all times if she had a seizure. New medication improved things and Alice was eventually able to complete mostly full weeks at school.

In June 2015 Alice was referred on to a Children's Epilepsy Surgery Service (CESS), one of 4 in the country, for decision whether she would be eligible for epilepsy surgery. The family were supposed to have heard the decision by September but in May 2016 there had still been no outcome.

Talking to Ed, the following things really impact on the family as a result of Alice's epilepsy:

The unknown – Waiting on the decision from CESS centre means that they feel unable to move forward. They are in limbo and do not know whether Alice will have to cope with her epilepsy forever or whether an operation could “fix her”. Their biggest fear is that they will not make a decision and will give them the option to decide. They want the experts to tell them what the next step is.

Sleep deprivation – Ed and Sam take it in turns to watch Alice sleep when she is fitting to ensure that she is ok. This means that they do not have a normal sleep pattern and James often sleeps in with the other parent as they “do not want him to feel pushed aside as a result of Alice's epilepsy”.

Speed of support – The nature of epilepsy is that a patient needs appointments when they are in status, not when they are good. Ed and Sam have access to the epilepsy specialist nurse team at Southampton but feel that others in hospital may need their time more if they have a question and so sometimes do not contact

General Communication – Clinic letters regularly take approximately 3 weeks to get processed and sent to the GP. This means that the GP will not amend any medication until the letter is received, delaying important changes to a regime that could improve Alice's quality of life.

Family suggestions for improvement

- Access to a community support team who could be a link into the hospital. Does not necessarily need to be an Epilepsy specialist but more of a case manager to help with any school liaison, general questions and be on the end of the phone for the family
- Improved turnaround of clinic letters or change of protocol for GPs to amend medication in a timelier manner
- Improved turnaround times for clinical decision



Dates for **your** diary – upcoming events for 2016

4 July

- **Paediatric Critical Care ODN Board Meeting**

7 July

- **Paediatric Neuro-rehab Research Day**
Boardroom, 1st Floor, Nuffield Orthopaedic Centre

28 July

- **Cardiac ODN Board Meeting**
Level D, UHS

1 August

- **2nd Paediatric Neurosciences ODN Board Meeting**
TBC

9 August

- **Southampton Oxford Retrieval Team (SORT) Meeting**
UHS

8 September

- **Thames Valley Paediatric Critical Care Forum**
TBC

12 September

- **Wessex Paediatric Critical Care Forum**
Oakley Road

19-23 September

- **PET (Paediatric Epilepsy Training) Week**
Leonard Wolfson Auditorium, Wolfson College,
Linton Road, Oxford, OX2 6UD

20 September

- **Paed Neurosciences ODN Charity Network Day**
TBC

29 September

- **ORENG (Oxford Regional Epilepsy Network Group) Autumn meeting**
TBC

10 October

- **Paediatric Critical Care ODN Board**
Tidbury

4 November

- **WPNCN (Wessex Paediatric Neurosciences Clinical Network) Neurosciences Study Day**
Education Centre, RHCH, Winchester

8 November

- **Southampton Oxford Retrieval Team (SORT) Meeting**
OUH

14 November

- **Wessex Paediatric Critical Care Forum**
Oakley Road

Children's Hospitals Network

*Providing a sustainable Clinical Network
Delivering healthcare to patients requiring Specialist Services*

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