

## YORKSHIRE & HUMBER NEONATAL ODN CLINICAL FORUM (NORTH)

**TUESDAY 5 FEBRUARY 2019, 9.00 AM - 11:00 AM**  
**HATFEILD HALL, WAKEFIELD, WF3 4JP**

Present		Apologies
<ul style="list-style-type: none"> <li>• Ashley Jennings, Information Analyst, Y&amp;H Neonatal ODN</li> <li>• Chris Day, Consultant Neonatologist, Clinical Lead, Bradford/Y&amp;H Neonatal ODN</li> <li>• David Gibson, Consultant Neonatologist, Mid Yorks</li> <li>• Eamonn Sheridan, Consultant Geneticist, Leeds</li> <li>• Eilean Crosbie (Chair), Paediatric Consultant, Neonatal Lead, Calderdale</li> <li>• Hazel Talbot, Consultant/Education &amp; Guideline Lead, Embrace Transport Service/Y&amp;H Neonatal ODN</li> <li>• Jo Preece (Secretary), Neonatal Consultant, Clinical Lead, Hull</li> <li>• Lisa Gorry, Project Lead, Y&amp;H Neonatal ODN</li> <li>• Liz McKechnie, Consultant Neonatologist, Leeds</li> <li>• Matthew Babierecki, Paediatric Consultant, Airedale</li> <li>• Sam Wallis, Paediatric Consultant, Bradford</li> <li>• Shameel Mattara, Paediatric Consultant, Calderdale</li> </ul>		<p>Sunita Seal, Consultant Neonatologist, Bradford</p>
No.	Item	Action
1.	<u>Minutes of the previous meeting – 10 July 2018</u> <ul style="list-style-type: none"> <li>• Agreed as an accurate record of the meeting.</li> </ul>	
2.	<u>Matters Arising</u> <ul style="list-style-type: none"> <li>• Renal Abnormalities - Discussion between South and North parts of YNN to fit with local practices. A draft version is nearing completion. <b>SW to forward final draft for review.</b></li> </ul>	<b>SW</b>
3.	<u>Genetics Presentation - Eamonn Sheridan – Medical Director YHNE Genomic Laboratory Hub</u> <ul style="list-style-type: none"> <li>• Explained current processes for gene testing and recent changes. In this region, Leeds Sheffield &amp; Newcastle are amalgamated into a single testing lab.</li> <li>• New changes should include urgent testing for sick children on NICUs and PICUs but details are to be confirmed. Diagnostic yield using new techniques is potentially high (30-40%).</li> <li>• New approach (next generation sequencing) will allow testing of a number of conditions in parallel. Turn around can be up to 80 days, therefore for single gene disorders an urgent service of around 3 weeks turnaround is proposed.</li> <li>• Eventual aim is for whole genome sequencing but currently only exome sequencing is offered in order to identify disease causing genotypes rather than normal variation.</li> <li>• NHSE has produced a test directory which outlines which conditions can be tested for. Group of conditions are defined. Possible monogenic disorders for</li> </ul>	

	<p>babies on NICU, with genetic opinion (discussion or direct review) and where a diagnosis will impact management will receive more rapid testing under the guise of "specialist services". Funded by NHSE. Launch date should be April 2019 with Exeter and GOSH providing services in meantime until rapid service is available. (Monogenic disorders do not include disorders with repeats such as myotonic dystrophy).</p> <ul style="list-style-type: none"> <li>○ Array CGH – Newcastle for single gene testing</li> <li>○ Core tests and processing of DNA samples – Leeds</li> <li>○ Specialist tests – Sheffield.</li> <li>○ June-Oct 2019 – whole genome sequencing – Cambridge</li> </ul> <ul style="list-style-type: none"> <li>● Proposal is that there needs to be a forum for discussing results and clinical meaning.</li> <li>● Exeter lab also proposing that for exome testing, trinomic testing is needed (samples required from both parents and child). This allows interpretation where consanguinity may be a factor. If 3 samples not available, a panel-based analysis will be carried out instead (for singletons and duos). Therefore there is a need to discuss with clinical genetics to ensure correct clinical and genetic information is sent with the samples.</li> <li>● Will not report carrier status in either the child or adult or identification of adult onset disorders.</li> <li>● Blood and referral forms should be sent to local labs who will record on their LIMS forward to Leeds for extraction and further forwarding to specialist lab.</li> <li>● Request forms remain paper but will transfer to online later in 2019 via National Genetic information services (NGIS). Phenotype descriptions will need identification using the HPO (Human Phenotype Ontology) coding system.</li> <li>● Discussions in process about clinical MDT that is effective in real time for interpretation of results.</li> <li>● <b>Action - Attendees to disseminate to local units. Recommendation is for all genetic testing requests to be arranged via the relevant clinical geneticists for each hospital.</b></li> </ul>	ALL
4.	<p><u>Transformation Update</u></p> <ul style="list-style-type: none"> <li>● Discussion on Better Neonatal Care document – still in draft form as governance process is being finalised. Financing of services in future is not yet decided and will depend on finalising of tariffs etc.</li> <li>● The Network are looking at implications of this document for units within the region. Final publication anticipated for April 2019.</li> <li>● 1/4/19 – will move to 2016 HRG definitions though locally in short term income will be protected until the national tariff starts. (Using the data collected in Dec 16 – April 17 period). Shadow period for national tariff starts April 2020 with implementation in April 2021.</li> </ul>	
5.	<p><u>Guideline &amp; Education Update</u></p> <ul style="list-style-type: none"> <li>● CD expressed need for basic guideline for early management of babies with PPHN/HIE. Network guideline is close to completion.</li> <li>● Further details in later part of the meeting.</li> <li>● <b>Network Annual Conference 2019 - 25<sup>th</sup> April 2019.</b> Registration is now open and abstracts have been requested from units. A Save the Date has been circulated and a programme will follow shortly.</li> <li>● The International Family Integrated Care Conference, will be held in Leeds 8 &amp; 9 October 2019. Further information to follow.</li> </ul>	
6.	<p><u>AOB</u></p> <ul style="list-style-type: none"> <li>● It was agreed during the meeting to reschedule the next forum date from 8 October 2019 to 15 October 2019. <b>Post Meeting Note: Unfortunately</b></li> </ul>	ALL



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	<b><i>Hatfeild Hall is unavailable on 15 October – therefore date for October meeting tbc in the near future once agreed.</i></b>	
7.	<u>Cheisi Product Presentation – Jennifer Copeland, Senior Hospital Specialist, Chiesi Limited</u>	
8.	<u>Dates of Future Meetings</u>  <i>All future Clinical Forum North Meetings will be held jointly with Nursing staff. Mortality Review Panel Group Meetings will follow 1.30pm to 4pm</i>  <ul style="list-style-type: none"><li>• 9 April 2019, Hatfeild Hall, Wakefield, 9am to 1pm</li><li>• 25 June 2019, Hatfeild Hall, Wakefield, 9am to 1pm</li><li>• October 2019 – Date to be confirmed</li></ul>	

*This meeting has been supported by Chiesi through the purchase of exhibition space*

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