

**MINUTES OF THE
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP
HELD ON THURSDAY 28 FEB 2019**

The Copthorne Hotel, Paradise Circus, Birmingham B3 3HJ

Present:

Hannah Bartlett-Syree	HBS	Acting Team Manager South Central ODT, NHSBT
Caroline Davidson	CD	CLOD and PICU Consultant, St George's University Hospitals, NHS Foundation Trust
Jan Dudley	JD	Paediatric Nephrologist, UH Bristol NHS Trust and Chair Paediatric Kidney Advisory Group
Jane Gill	JG	CLOD and Neonatologist, University Hospitals of Leicester, NHS
Annabel Greenwood	AG	Paediatric S4 Trainee, University of Wales, Cardiff
Neil Healy	NH	SNOD Scotland ODT, Scottish Representative, NHSBT
Sally Holmes	SH	Professional Development Specialist, ODT, NHSBT
Riaz Kayani	RK	CLOD and PICU Consultant, Addenbrookes Hospital, NHS
Sue Madden	SM	Senior Statistician, NHSBT
Ajit Mahaveer	AM	Consultant Neonatologist, Central Manchester University Hospital, NHS
Chris Kidson	CK	CLOD and PICU Consultant, Greater Glasgow and Clyde, NHS
Jo Wright	JW	Neonatologist, Leeds Teaching Hospital, NHS
Reinout Mildner	RM	National Paediatric CLOD, PNODC Chair and PICU Consultant Birmingham Children's Hospital
Nagarajan Muthialu	MN	Consultant Cardiothoracic Surgeon, Great Ormond Street Hospital, NHS
Naga Puppala	NKP	CLOD and PICU Consultant, Alder Hey Children's Hospital, NHS
Angie Scales	AS	Lead Nurse Paediatric and Neonatal Donation and PNODC Co-Chair
Jon Smith	JS	Paediatric Anaesthetist, Freeman Hospital Newcastle, NHS
Simon Steel	SS	CLOD and PICU Consultant & Anaesthetist, Sheffield Children's Hospital, NHS
Carli Whittaker	CW	Paediatric Intensive Care Society (PICS) Nurse Representative
Fiona Wellington	FW	Assistant Director, Organ Donation & Nursing, NHSBT
Dale Gardiner	DG	National CLOD, NHSBT
In attendance:		
Heather Crocombe	HC	Clinical & Support Services, NHSBT
Hannah Westoby	HW	Clinical & Support Services, NHSBT

Apologies:

Apologies were received from Cherry Brown, Suzanne Brown, Joe Brierley, Anthony Clarkson, Becca Curtis, Aniko Deierl, Matthew Fenton, Michael Griksaitis, Michelle Jardine, Yemi Jegede, Chris Kearns, Debbie Macklam, Dawn McKimm, Catherine Penrose, Ella Poppitt, Stewart Reid, Simon Ruby, Simon Robinson, Magrid Schindler

		ACTION
1	Welcome, Introduction and Apologies RM welcomed everyone to the meeting and gave details of apologies received.	

		ACTION
2	<p>Review of previous Minutes and Action Points (NODCPSTG(M)(18)2) and NODCPSTG(AP)(18)2) Minutes were approved. It was agreed that actions points were incorporated in the agenda.</p>	
3	<p>Matters Arising <u>Banners and Leaflets, electronic media</u> Leaflets are now available to order through the website. There is currently a paediatric specific banner available which can be ordered through SNODs. This shows Jemima, 13, who donated the highest number of organs after death recorded. Other banners can be created if people have specific requirements, costing should be agreed with ODT teams. The e-media slide show has been recirculated by AS to all SNODS. This item can be removed from the AP.</p> <p><u>Determination of Death by Neurological Criteria Forms</u> NODC Paediatric sub-group has previously agreed a version 1 of the form which is available at www.odt.nhs.uk. The group have sought ratification of v2 from the Royal College of Paediatric and Child Health (RCPCH) and British Association of Perinatal Medicine (BAPM). RCPCH they have come back on two occasions with separate requests for changes. RM to contact RCPCH directly to discuss these requests further.</p> <p><u>DCD Donation under 1 Month</u> NHSBT Kidney Advisory Group (KAG) recommendations in 2017 agreed there would be two centres (Leeds and Guys) identified to carry out renal transplantation where donors were infants less than 2 years of age. A further review in Nov 2018 supported these recommendations with an additional agreement that the lower limit for renal acceptance should be 1 month corrected gestational age. Leeds and Guys should remain the identified transplant centres for renal transplantation from donors between 1 month and under 2 years old. The process documents have been updated to reflect this change and greater guidance for SNODs on organ suitability for small infants. Kidneys from infants less than 1 month old are not currently considered for renal transplantation as advised by KAG. Hepatocyte only donation is supported by NHSBT senior management team. The benefits of hepatocyte donation and transplantation from small infants is significant, described as a 'game changer' by the leading centre in this area, this information should be relayed to clinical teams and families.</p> <p>RM met with John Dark and discussed the OCS system where DCD hearts can be supported post donation. The Newcastle research group is working on the use of this technology even for small infant donors.</p> <p><u>Information Sharing</u> Discussion took place at the last meeting as to whether a forum group should be set up in order to share information. Today's attendees agreed that this is not necessary for now, and that as the Strategy is being developed, information sharing will become clearer. This item can be removed from the AP.</p> <p><u>Videos for Determination of Death by Neurological Criteria</u> These are now available at www.odt.nhs.uk and are proving to be a very useful tool.</p>	<p>HC</p> <p>RM</p> <p>HC</p>

		ACTION
	<p>Neonatal ICU Audit</p> <p>It is currently not possible to fully capture all potential donor audit data from the BadgerNet system. As a result of meetings AM has held with various people regarding this, it does seem possible to extract data and add extra fields as needed. No quote for the cost of this has been received as yet. This item is a recommendation in the strategy and AM agreed to continue to work towards a resolution.</p> <p>The Potential Donor Audit is in the process of being updated, AS inputted into this update in regard to any changes required specifically for paediatric patients and in an attempt to pre-empt any changes that we need to capture in moving forward with the Strategy recommendations.</p> <p>Data from neonatal units continues to be excluded from formal reports but can be captured and requested as required.</p>	AM
4	<p>PNODC Membership and Terms of Reference</p> <ul style="list-style-type: none"> We need to ensure membership of PNODC enables delivery of the strategic plan and includes appropriate representation from stakeholders All operational regions should be fully represented Suggested there should be a core membership with associated invited members SS suggested more regional collaborative groups could be set up to feed into PNODC Lay Representation should be included Terms of reference need to be reviewed fully 	RM/ AS
5	<p>Paediatric CLOD Role Description</p> <p>A formal paediatric CLOD role description was circulated to the group for comments. Following agreement, it will be circulated for use.</p>	AS
6	<p>Paediatric Donation and Transplantation Annual Data Report 2017-18</p> <p>SM presented this Annual Data Report.</p> <p>Please see paper for details. However, summary:</p> <ul style="list-style-type: none"> Between 1 April 2017 and 31 March 2018, there were 1,204 paediatric deaths audited for the PDA 110 and 224 patients met the referral criteria for DBD and/or DCD respectively. 95% and 84% were referred to a SNOD Consent/authorisation was obtained from families for 62% eligible DBD donors and 38% eligible DCD donors At 31 March 2018 there were 130 paediatric patients on the transplant list 1 April 2017 to 31 March 2018, 283 paediatric patients received a transplant Number of paediatric patients transplanted was similar in 2017/18 and 2016/17 <p>RM thanked SM for all the work she had done in order to produce this report. The report will be uploaded at www.odt.nhs.uk</p>	SM

		ACTION
	Neonatal ITU activity is not reported currently on this Stats report – SM advised separate data could be presented as required.	SM
7	<p>Paediatric and Neonatal Trainee Reps TROD Initiative</p> <p>AG is an ST4 Paediatric Trainee with Cardiff & Vale Health Board and gave a presentation to outline the work she has been doing, looking at paediatric and neonatal organ donation from a paediatric medical trainee perspective. Please see paper for detail, but to summarise:</p> <ul style="list-style-type: none"> • There is limited knowledge of organ donation amongst paediatric trainees • There is a desire and enthusiasm from those trainees to learn more • Set up regional teaching programme • Establish National TROD role • UK-wide OD teaching programme <p>RM offered AG his congratulations on the work she has carried out so far.</p>	
	~ Lunch ~	
8	<p>Strategy Timeline</p> <p>Formal launch of the strategy takes place next week (w/c March 4th) with launch date March 7th at the joint BTS/NHSBT congress.</p> <p>An invitational meeting is planned for the summer, original date requires amendment, but the final details will be circulated as soon as possible.</p>	
9	<p>Media Plan</p> <p>AS gave a comprehensive update of the media release and plans for engagement over the course of the formal release of the Paediatric and Neonatal Deceased Donation Strategy.</p> <p>This includes ministerial support, national and local coverage. Media release currently under embargo until March 4th.</p> <p>If there are any families currently awaiting transplant who would be happy to be involved, please let AS know.</p>	All
10	<p>Strategic Plan – Prioritisation and Allocation of Work Streams</p> <p>The meeting split into three identified work streams, each group tasked with prioritising the actions identified in Appendix A / B of the strategic plan. The workstreams were: Structural, Operational and Educational</p> <p>The outputs from this will be further discussed and an agreed plan for initial delivery of the strategic recommendations circulated to the group.</p>	AS
11	Any Other Business	

		ACTION
	<p>Retrieval Team Triggers</p> <p>SS raised the need for guidance for early discussion between retrieval teams and SNODs where children are identified with devastating brain injury at local hospitals. This will ensure that all options including organ donation are discussed with families where donation may be possible. Discussion focussed on the need to follow current best practice, which is admitting this group children to PICU for detailed assessment and prognostication over a period of time to improve accuracy. The experience in adult neuro-critical care shows that early prognostication is not always accurate. Withdrawal by the retrieval team in the local hospital may therefore not be in the child's best interests. Referral to SNOD can still happen early if there are concerns about poor prognosis.</p> <p>SS is also performing a survey on parental and child attitudes to organ donation and will subsequently feed back to the group.</p> <p>CK noted that NH has accepted a new position in the Scottish Tissue Bank and will therefore be leaving NHSBT. Both CK / RM and the whole committee joined to thank NH for the huge contribution he has made to paediatric organ donation.</p>	
12	<p>Next Meeting: NODC Paediatric Sub-Group Wednesday 25 September 2019 One Park Crescent, London W1B 1SH</p>	