ORGAN DONATION & TRANSPLANTATION DIRECTORATE - NHS BLOOD & TRANSPLANT
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP

MONDAY 16TH NOVEMBER 2015
SCHOOL OF ORIENTAL & AFRICAN STUDIES (SOAS)
ROOM B202 IS LOCATED IN THE BLOOMSBURY SUITE, 2ND FLOOR OF THE BRUNEI GALLERY, THORNHAUGH ST, RUSSELL SQUARE, LONDON, WC1H 0XG

PRESENT:

Kay C Hawkins	(KCH)	Paediatric Clinical Lead for Organ Donation
Paul Murphy	(PM)	National Clinical Lead for Organ Donation
Paul Baines	(PB)	CLOD and PICU Consultant, Alder Hey Hospital
Anthony Clarkson	(AC)	Associate Director for Organ Donation and Nursing
Caroline Davison	(CD)	CLOD St George's University Hospitals NHS Foundation Trust
Rachel Hodge	(RH)	Specialist Nurse Organ Donation, Birmingham Children's Hospital
Riaz Kayani	(RK)	CLOD and PICU Consultant, Cambridge
Chris Kearns	(CK)	Clinical Lead for Organ Donation, Oxford
Nicos Kessaris	(NK)	Paediatric Renal Transplant surgeon, Guy's and St Thomas
Chris Kidson	(CK)	Clinical Lead for Organ Donation Glasgow
Reinout Mildner	(RM)	Consultant Paediatric Intensivist, Birmingham
Ajit Mahaveer	(AM)	Consultant Neonatologist, Central Manchester University Hospital
Nagarajan Muthialu	(NM)	Consultant Cardiothoracic Surgeon, Great Ormond Street Hospital
Catherine Penrose	(CP)	CLOD and PICU Consultant, Leeds General Infirmary
Angie Scales	(AS)	Practice Development Specialist, NHSBT
Maggie Stratton	(MS)	Communications, NHSBT
Simon Steel	(SS)	CLOD and PICU Consultant & Anaesthesia, Sheffield
Simon Robinson	(SR)	CLOD and Paediatric Intensivist & ECMO Consultant Leicester
Joe Wright	(JW)	Consultant Neonatologist Leeds Teaching Hospital

IN ATTENDANCE:

Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT

Item	Title	
1.	**Welcome introduction, apologies and objectives for the meeting**	
	KCH welcomed the group and thanked them for attending. Apologies received from Jayne Fisher, Fiona Wellington, Simon Raby, Stephen Marks, Margrid Schindler and Aniko Deierl	
		ACTION
2.	**Background to Paediatric National Organ Donation Committee** PM advised the group that there had been several triggers to the establishment of the paediatric sub-group including: • The increase in the number of children on Cardiothoracic ITUs on mechanical devices waiting for a heart transplant. • The publication in April 2015 of the guidelines from the RCPCH on the diagnosis of death by neurological criteria in infants less than two months old. • The increase in the number of referrals from the neonatal population.	

	The remit of this committee is to act as a source of advice and assistance to NHSBT in the development of strategies to increase organ, corneal and tissue donation from potential paediatric and neonatal donors and to work with NHSBT staff and other professional bodies to support their implantation. It will report to the National Organ Donation Committee. Discussion took place identifying the potential for organ and tissue donation from children in the UK. It was noted that compared to adult solid organ donation, there are fewer paediatric organ donors in the UK and even less from the neonatal population. It was also recognised that any expansion of paediatric organ and tissue donation and transplantation in the UK will have wide implications for services such as organ retrieval and transplantation.	
3.	**Terms of Reference and Membership**	
	PM discussed the proposed Terms of Reference of the Paediatric Sub Group of NODC which had been circulated before the meeting. Members were asked to comment on the TOR and membership list proposed. **Agreed Terms of Reference** • To act as a source of advice and assistance to NHSBT in the development of strategies to increase organ, corneal and tissue donation from potential paediatric and neonatal donors and to work with NHSBT staff and the wider NHS to support their implementation. • To provide a forum for identifying and spreading best practice across the UK with regard to donation from paediatric patients • To lead the design and delivery of training and development opportunities for clinical staff involved in the care of potential deceased paediatric organ donors, including (but not limited to) – Refresher courses for CLODs and Donation Committee Chairs associated with hospitals where Paediatric and neonatal organ donation is a possibility. – Induction courses for newly appointed paediatric CLODs – Paediatric sessions within the National Donation Congress – Provision of bespoke areas within the NHSBT organ donation microsite and organ donation toolkit • To assist NHSBT to improve and optimise all aspects of paediatric donation, including both the strategies recommended by the Organ Donation Taskforce, the ‘six big wins’, and any further initiatives to increase organ donation identified by the Committee or arising from the TOT2020 strategy. These will include but not be limited to improvements in: – The identification and timely referral of all potential solid organ donors in neonatal and paediatric intensive care units and in other clinical areas such as (but not restricted to) Departments of Emergency Medicine. – The neurological determination of death in all possible cases – The physiological optimisation of potential brain dead donors, including intra-operative care. – Donation after circulatory death. – The planning and delivery of the family approach for consent / authorisation for donation in collaboration with the specialist nurse for organ donation.	

	– Provision of standardised documentation to support clinical practice relating to diagnosis of death, donor optimisation, planning for family approach. • To promote effective dialogue and collaboration between relevant professional groups and the Colleges and Societies that may represent them, including paediatric and neonatal intensive care, paediatric anaesthesia, paediatrics and child health, emergency medicine, critical care nursing, neurosurgery and retrieval / transplantation. • To sponsor and support research, development and audit relevant to deceased donation, including (but not limited to) the analysis and future development of the Potential Donor Audit. • To ensure that donation from infants with anencephaly and other lethal abnormalities takes place wherever and whenever possible subject to family and parental wishes. **<u>Agreed membership</u>** • Paediatric Clinical Lead for Organ Donation (Chair) • National Clinical Lead for Organ Donation, • Associate Director for Organ Donation and Transplantation • NHSBT - Practice Development Specialist • NHSBT - Team Manager – Paediatric Interest. • Clinical Leads – Organ Donation from Regional Lead Centres for Paediatric Critical Care (across the four DAs) • UKDEC representative • Chair of Paediatric SN-OD working Group • Professor/Consultant Neonatologist • Neonatal Nurses Association • Paediatric Cardiothoracic Transplant Surgeon • Paediatric Renal Transplant surgeon • BAPM / PICS retrieval-transport subgroups (paediatric and neonatal) • PICS nursing council • NHSBT stats • NHSBT media / Communications • Professional bodies: **PICS**; BAPM; APA**; RCPCH**; BMFMS	
4.	**Understanding the opportunities for donation from children and the demand for transplantation**	
	Joe Wright (Leeds) and Angie Scales (London) presented local and national data. A Scales presented audit data on the potential for solid organ donation from the majority of specialist neonatal units in London, identifying the following barriers: - SNOD confidence and understanding of neonatal intensive care delivery. - Access to data - Absence of clear identification and referral process. A Scales to consider including time of death diagnosis when collecting data in the future. J Wright presented audit data for the potential for neonatal in Leeds from July 2010 to June 2015. It was noted that Boston data is the only published data currently available. Of the 199 audited deaths, the possibility of donation was excluded from 145 neonates on the basis of size (< 2.5kg) or gestational age (< 35 weeks). A further 36 were excluded as a result of mode of death or parental wishes, leaving a potential of 18 possible donors (14 DCD and 4 DBD) over a five year period from a single level 3 NICU.	

	P Murphy presented the PDA data for donation from children for 2013 – 2014. The Committee recognised key limitations of the data, particularly the minimal data from neonatal ICUs, and also a need to present the data by age in a way that is meaningful to clinical practice. The high number of refusals by Coroners / Procurators Fiscal (in part because of hypoxic ischemic encephalopathy or possible non-accidental injury) was noted. It was noted that the quality of organs from infant donors was higher and had a better outcome than those from adult donors. There was also a view that some potential donors die outside intensive care units (e.g. in hospices).	
5.	**Work streams – suggestions**	
	After discussion Members agreed the following workstreams below: 1. Paediatric and neonatal organ donation pathway. An operational document to assist all involved in the clinical care of paediatric patients (all ages) who have the potential to be organ donors. Local guidelines already in use/developed to be shared with the group to hopefully allow development of a national guideline. **ACTION: All to send any locally developed guidelines or policies with regard to paediatric organ donation to the group via Ambreen Iqbal.** **2.** Review current PDA data for paediatric population. Consider any changes necessary to answer questions about the identification, referral, brain stem death testing and consent rates within the paediatric population for consent rates. **3.** R Mildner has secured funding to visit the USA – specifically three centres with high consent rates. R Mildner to report back to the group. **4.** Brain stem death testing – circulate documentation developed by Dale Gardiner. Seek ratification by PICS. **5.** Develop a paediatric section on the ODT Microsite.	R Mildner & S Robinson All K Hawkins & seconded Paediatric SNOD R Mildner K Hawkins A Scales & M Stratton
6.	**Next steps and future working arrangement**	
	The next NODC sub group meeting to be arranged in March 2016, 11:00 -15:00, London	A Iqbal
7.	**Any Other Business**	
	No matters were reported under AOB	