

**MINUTES OF THE
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP
HELD ON TUESDAY 26th SEPTEMBER 2017**

The Medical Society of London, Lettsom House,
11 Chandos St, Marylebone, London, W1G 9EB

PRESENT:

Kay C Hawkins	(KCH)	Paediatric Clinical Lead for Organ Donation (Chair)
Joe Brierley	(JB)	CLOD Great Ormond Street
Cherry Brown	(CB)	Senior Media & PR Officer, NHSBT
Anthony Clarkson	(AC)	Assistant Director Organ Donation and Nursing, NHSBT
Chris Kidson	(CK)	CLOD Royal Hospital for Children Glasgow
Caroline Davison	(CD)	CLOD St George's University Hospitals NHS Foundation Trust
Jayne Fisher	(JF)	Team Manager, Yorkshire
Reinout Mildner	(RM)	CLOD Birmingham Children's Hospital
Ajit Mahaveer	(AM)	Consultant Neonatologist, Central Manchester University Hospital
Debbie McGuckin	(DM)	Senior Commissioning Manager - ODT
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation NHSBT
Jon H Smith	(JHS)	Paediatric CT anaesthesia / ECMO, Freeman Hospital
Catherine Penrose	(CP)	CLOD Leeds General Infirmary
Louise Bruce-Tresnan	(LBT)	Deputising for Cherry Brown, Corporate Communications
Sue Madden	(SM)	Senior Statistician, NHSBT
Joanna Wright	(JW)	Consultant Neonatologist, Leeds Teaching Hospital
Caron Watts	(CW)	Advanced Neonatal Nurse Practitioner Doncaster and Bassetlaw Teaching Hospitals, Representing the Neonatal Nurses Association,
Sally Holmes	(SH)	Deputy for H Bartlett - Professional Development Specialist, NHSBT
Neil Healy	(NH)	Specialist Nurse - Organ Donation, Scottish Representative NHSBT
Nagarajan Muthialu	(NM)	Consultant Cardiothoracic Surgeon, Great Ormond Street Hospital for Children
Carli Whittaker	(CW)	Paediatric Intensive Care Society (PICS) Nurse Representative
Ella Poppitt	(EP)	Assistant Director Governance and Clinical Effectiveness Clinical Directorate

IN ATTENDANCE:

Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT
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Item	Title	ACTION
1.	Welcome introduction and apologies	
1.1	K C Hawkins welcomed everyone to the meeting and noted the apologies given for this meeting. Apologies have been received from Paul Baines, Rebecca Curtis, Aniko Deierl, Katja Empson, Stephen Marks, Dawn McKimm, Esther Wong, Judith Van Der Voort, John Forsythe, Simon Raby, Simon Robinson, Simon Steel, Hannah Bartlett - Syree, Michael Griksaitis, Yemi Jegede, Riaz Kayani, Chris Kearns, Paul Murphy and Magrid Schindler Welcome extended to Carli Whittaker who has joined the committee as a Paediatric Intensive Care Society (PICS) nurse representative. K Hawkins advised that an open seat is now available for anyone wishing to attend the meeting as an observer.	
2.	Review of previous minutes and action points	
2.1	The minutes from the last meeting were agreed as a true and accurate record of the meeting, subject to the following amendment: add Chris Kidson to the attendees list.	A Iqbal
3.	Matters arising	
3.1	Banners and leaflets J Fisher summarised that the leaflets are now completed and available and accessible through the NHSBT's website.	

J Fisher reported that actions re banners is currently on hold due to low staff capacity to proceed with this task, however an agreement was reached to move this forward. Consensus was reached that the Trusts would also be keen to introduce multimedia advertisement as well as display banners in the paediatric units represented. An update will be available at the next meeting.

J Fisher /
C Brown

3.2

Launch of new website for ordering leaflets

Refer to banners and leaflets above.

A link was noted for ordering leaflets.

<https://www.nhsbtleaflets.co.uk/Home.html>

3.3

NHSBT website update

The committee was informed that the clinical website has been updated significantly. Many who have accessed it commented that it is easier to navigate than the previous one. The website now includes additional information on neonatal and paediatric patients. Members are encouraged to view the website and feedback any comments. www.odt.nhs.uk

3.4

Paediatric Level Meeting Data Report

Following amendments at the last meeting the Paediatric level meeting data report has now been revised and finalised. This is also available online.

<https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/4499/paediatric-units-meeting-booklet-apr-2017.pdf>

It was acknowledged that the level data meeting will be reviewed annually.

4.

4.1

Coroners

In J Forsythe absence K Hawkins reported on his behalf. NHSBT will continue to build on establishing an effective working relationship with the Chief Coroner. J Forsythe attended a Coroners' Continuation Training in June along with Becky Clarke, Team manager South Central.

The Chief coroner is in the process of drafting guidelines for coroners to refer to regarding the agreement on organ donation. It was agreed to await the guidelines before progressing on a number of previously agreed actions to ensure they are in line with the guidance. Members are encouraged to continue building up working relationships with their local coroners. It was noted that following the recent tragedy in Manchester, a senior Coroner from Bolton was requested to deal with cases where organ donation may have been possible and assist with the discussion regarding organ donation possibilities.

Members raised concerns that not all coroner refusals are captured and members are asked to report and highlight such cases.

It was established that coroner's refusal may also be an outcome of a decision made by a forensic/Home Office pathologist and it is crucial to ensure that communication and engagement extends to this group.

4.2

Media Update / Organ Donation Week

C Brown provided an update of forthcoming campaigns to promote organ donation and raise awareness.

Several personal stories about organ donation and transplantation have been powerful in encouraging the public to join the NHS Organ Donor Register or trigger people to talk about organ donation.

Members were advised that NHSBT have collaborated a partnership with a Bollywood concert and stars of the show have filmed personal messages to promote donation.

The Organ Donation week took place beginning of September with encouraging rise in registrations which appear to have doubled compared to last year. Members were informed of on-going case studies being available from NHSBT and were asked specifically to forward any case studies from the BAME community.

A statistical analysis was carried out looking at data on children waiting for a

heart transplant. The data will be used for the World Heart Day taking place on 29th September every year and is a chance for people across the globe to take part in the world's biggest intervention against cardiovascular disease. Members recognised the ongoing work with NHS Blood and Transplant to promote organ donation to all its staff, patients and visitors within units however concerns were raised that hospitals do not have enough supplies of lift wraps. The time frame has been extended for this initiative and C Brown to advise K Hawkins.

C Brown

4.3 **Neonatal Audit Update**

Following detailed discussion at the last meeting, strong emphasis was made for the need to audit across all level 3 neonatal units. A Scales reported that data is now being audited in approximately 30% of units. A Mahaveer has been looking at the data collected by BadgerNet and will continue to work with A Scales to establish how the data collated in NICUs may be used to assist in the PDA data collection.

The RCPCH was approached following the release of the neurological determination of death guidance for infants less than two months old. The College was asked if there was an intention to audit compliance with guidance. Due to shortage of resources the College is unable to assist with this at the present time. It was noted that BadgerNet does not capture neurological determination of death testing.

4.4 **Devolved Administration Updates:**

Scotland update

N Healey informed members that the Scottish paediatric organ donation guidance is being updated and currently in the process of rolling out testing for these documents in NHS Lothian and NHS Glasgow. Any feedback comments received will be reviewed by the Scottish Government and the neurological determination of death testing guidance will be pulled together by November, with a launch date in February next year. The guidance will be available on the Organ Donation Scotland website. The Crown Office Procurator Fiscal Agreement on organ and tissue donation with Scottish Donation Transplant Group is being updated.

Wales update

4.5 K Hawkins gave an update on behalf of Wales and advised members that Wales are producing a neonatal organ donation pathway to help trainees and consultants think about donation and provide them with easy steps to undertake the process. This involves all three tertiary neonatal units.

There are several Quality Improvement projects which are helping to facilitate awareness amongst trainees, and neonatal presentations have been carried out at both regional and local meetings, including 'Towards 2020' at the Welsh Government Organ Donation Conference.

It was noted that with help from NHSBT two eye-catching wall mounts from an infant and child who donated have been produced and displayed within PICU and NICU.

J Van Der Voort recently attended the first presentation of the study 'Understanding family attitudes and experiences of the new deemed consent act for organ donation in Wales', the study presented interesting findings.

Northern Ireland update

4.6 It was acknowledged that there was no representation from Northern Ireland at the meeting; no update has been made available.

KAG Report on EBKT < 2 years

4.7 The committee received and discussed the KAG report on EBKT <2 years of age which was presented at the Kidney Advisory Group meeting in June 2017. Members noted the 10 recommendations which were accepted by the KAG committee, further work continues to implement the recommendations.

A Scales

5. Education and training**5.1 Regional CL-OD Education and Training**

Members were informed that a Regional CLOD for education and training job has been advertised, the role description has an emphasis on simulation training.

Members enquired on the progress made with releasing the neurological determination of death video project. A Scales to liaise with D Gardiner and update at the next meeting.

A Scales

6. Ongoing Work streams**6.1 Neurological Determination of Death testing forms**

Members noted the completion of the forms for both Under 2 months and 2 months to 18 years. The forms have been endorsed by FICM, NODC, NODC Paediatric and UKPICS. The forms are available on the clinical website. Ratification by RCPCH and BAPM is in progress.

K Hawkins

6.2 Care Plan Update

The Care plan is undergoing minor changes to enable use on neonatal units; members are asked to feedback any further comments which will be incorporated in the Care Plan before being made available on the clinical website. A comment was raised around optimisation parameters for less than 1 month old which will be incorporated within the Care plan. Thanks were expressed to R Mildner for his hard work on this project.

6.3 Bench Marking Data 2015-17

The committee was provided with a bench marking data presentation slides for 1 April 2016 to 31 March 2017. The presentation slide included data from:

- Paediatric patients (aged 15 years or under) 2016/17
- Paediatric patients who died in a paediatric ICU 2016/17
- Deceased paediatric donors (aged 15 years or under)
2005/06 -2016/17
Paediatric patients (<18 years)
2016/17

The report will be made available on the clinical website.

6.4 Revised Trust / Board report

Revised Trust/Board reports were presented to the group. These reports now will include improvements in the presentation of paediatric ICU data. It was highlighted that one of the key amendment is the replacement of the current executive summary report with a one page automated letter from the NHSBT Chief Executive summarising the number of donors facilitated in the Trust and the number of transplants that results in, with reference to number of referrals and SNODS presence.

Attention was drawn to data section 6.6 Consent in the Detailed Report and it was suggested to add (adult and paediatric) in the agreed 2016/2017 overall **adult and paediatric** national targets for DBD and DCD.

S Madden

6.5 Paediatric and Neonatal Strategy - Stakeholder Engagement

A Scales presented a skeleton strategy for Paediatric and Neonatal donation and transplantation and requested comments/thoughts from the committee to form part of the ongoing stakeholder engagement. It was noted that this will be a strategy document to set out recommendations for paediatric and neonatal donation and transplantation which will work alongside the overall national strategy, 'Taking Transplantation to 2020'. A useful discussion around all elements of the process developed and the committee was asked to feedback any further comments for consideration to A Scales.

A Scales

7. Any other business

7.1 DCD heart donation

There were further discussions about the possibility of introducing DCD Heart donation from the paediatric community. Concerns were raised regarding availability of these organs for smaller children on the transplant waiting list. The committee is supportive of developments to improve transplantation and the transplanting centres were advised to submit any project proposals to RINTAG for discussion and approval.

The committee would like to register its regret that children are still dying waiting for a transplant and will continue to raise this within NHSBT.

8. Next Meeting

8.1 The next NODC Paediatric Sub Group will take place on Tuesday 30th January 2018, 11:00 – 15:00, Medical Society of London, Lettsom House, 11 Chandos St, Marylebone, London W1G 9EB