

**MINUTES OF THE
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP
HELD ON TUESDAY 30th January 2018**

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

PRESENT:

Kay C Hawkins	(KCH)	National Paediatric Clinical Lead for Organ Donation (Chair)
Rachel Newton	(RN)	Senior Media & PR Officer, NHSBT
Caroline Davison	(CD)	CLOD St George's University Hospitals NHS Foundation Trust
Reinout Mildner	(RM)	CLOD Birmingham Children's Hospital
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation NHSBT
Jon H Smith	(JHS)	Paediatric CT Anaesthesia / ECMO, Freeman Hospital
Riaz Kayani	(RK)	CLOD and PICU Consultant, Addenbrookes Hospital, Cambridge
Yemi Jegede	(YJ)	CLOD, Kings College Hospital, London
Simon Steel	(ST)	CLOD and PICU Consultant & Anaesthesia, Sheffield
Gail Melvin	(GM)	SNOD, Cardiff and Vale University Health Board
Jacob Simmonds	(JS)	Consultant Cardiologist and Transplant Physician, GOSH
Catherine Penrose	(CP)	CLOD Leeds General Infirmary
Magrid Schindler	(MS)	CLOD and PICU Consultant, Bristol
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,
Dawn McKimm	(DMc)	Representing Professional Development Specialist, NHSBT and Team managers / Regional Managers NHSBT
Neil Healy	(NH)	Specialist Nurse - Organ Donation, Scottish Representative NHSBT
Carli Whittaker	(CW)	Paediatric Intensive Care Society (PICS) Nurse Representative

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. Apologies have been received from Joe Brierley, Anthony Clarkson, Aniko Deierl, Stephen Marks, Sally Holmes, Debbie McGuckin, Nagarajan Muthialu, Julie Richardson, Teressa Tymkewycz, Caron Watts, Ajit Mahaveer, Chris Kidson, John Forsythe, Simon Raby, Simon Robinson, Hannah Bartlett - Syree, Michael Griksaitis, Chris Kearns and Paul Murphy. Additional and new attendees were welcomed to the meeting: Gail Melvin (Specialist Nurse in Organ Donation in Cardiff and Vale University Health Board) (Observer), Chris Callaghan (National Clinical Lead for Organ Utilisation (abdominal)) and Rachel Newton (Senior Communications Officer – Media and PR, NHSBT), and Jacob Simmonds (Representing GOSH Transplant Team)	
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.	
3.	Matters arising	
3.1	Banners and leaflets, electronic media K Hawkins informed members that the leaflets are now completed and accessible through the NHSBT's website. It was noted that some of the actions arising from previous discussions are still outstanding, these are provision of promotional banners and suitable electronic media for Trust use. S Steel, R Newton, N Healy and T Tymkewycz have agreed to take this forward and	S Steel/ R Newton/ N Healy/ T Tymkewycz

complete these actions. A link was noted for ordering leaflets.

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

3.2 **Care Plan - NODC PSG (18)1**

Members received a revised Care Plan which has been approved as version 2, this will be made available on the clinical website. A Scales has agreed to work with N Healy to adapt and tailor the current version of the Care Plan for use in Scotland.

A Scales

3.3 **Neurological Determination of Death Testing Forms**

Following feedback received from the RCPCH, version 1 of the form has now been modified. The forms are available on the clinical website. Ratification by RCPCH and BAPM is in progress.

3.4 **EBK developments in < 2 yr. old donors**

C Callaghan gave an update on the EBK developments in the UK.

At the June 2017 Kidney Advisory Group meeting, a report and recommendation was made for St James, Leeds and Guy's to be the national centres for implanting kidneys from small paediatric donors (<2yrs old). Since the report recommendation, the following developments have taken place:

- A team from Guy's visited Leeds to identify the processes and pathways and how organ offering should take place.
- A geographical model of allocation was decided the most appropriate.
- A zonal approach on North/South geographical split has been agreed, to form a closer relationship with the Paediatric intensive care teams and to minimize cold ischemic time.
- Based on recently analysed data on graft survival; acceptance criteria have been revised.

There is continued work to ensure utilisation of small infant organs in line with the utilisation strategy.

It was acknowledged that this has major implications for potential DCD donation in infants < 1 month old. A paper is pending presentation to SMT regarding hepatocyte only donation in small infants. Clearer guidance will be available following this meeting. A Scales will feedback any changes to the guidance in due course. C Callaghan to provide a further update in January 2019.

C Callaghan/
A Scales

3.5 **Consultation for Organ Donation Opt - Out System in England**

Members noted the Government's announcement to launch a consultation into a proposed opt - out organ donation system for England. Although members may be contributing through a national consultation organised by NHSBT, they are encouraged to make a personal response. For more information on the consultation and to share your views, visit:

<https://engage.dh.gov.uk/organdonation>

All

4. **Coroner Update**

4.1 **Chief Coroner Guidance**

In J Forsythe's absence K Hawkins reported on his behalf. Members noted the Chief Coroner Guidance No 26 for information. The purpose of this guidance is to help coroners with decision-making in situations that concern organ and tissue donation. It is intended to assist coroners on the law and procedures to be followed when dealing with post mortem organ and tissue donation, with a view to providing greater consistency of approach across all of England and Wales. Positive feedback has been received following the publication of the Chief Coroners Guidance. K Hawkins to provide an update at the NODC Paediatric meeting in September.

K Hawkins

4.2 **Media Update**

R Newton reported on two high profile cases. An update of forthcoming campaigns to promote organ donation and raise awareness was noted. A campaign named “Words Saves Lives” started in January 2018 and the aim is to encourage people to share their donation decision with their family. This campaign includes two paediatric case studies. Members were informed that NHSBT have collaborated a partnership with a card company Moonpig.com who are producing organ donation cards for Valentine’s Day. There is activity planned for World Kidney Day in March, their primarily focus will be around the decline in living donation.

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. G Melvin is working together with A Mahaveer to look 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. A further update will be provided at the next meeting.

G Melvin /
A Mahaveer /
A Scales

Devolved Administration Updates:

4.4 **Scotland update**

N Healy presented the Guidance for staff in Neonatal and Paediatric Intensive Care Units and other departments who may work with critically ill children or babies. Members also noted the following:

- Unborn Baby with Serious Abnormalities Organ and Tissue Donation Options – guidance for information.
- Agreement between Crown Office and Procurator Fiscal Service Scottish Donation and Transplant Group in regard to Organ and Tissue Donation.

The Guidances named above will be available on the Organ Donation Scotland website. A Scales noted it is crucial that the pending National Strategy and Scottish guidance is aligned.

4.5 **Wales Update**

It was noted that work has commenced in relation to developing 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 in Wales.

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.

G Melvin reported that three centres will start completing the PDA data. A Paediatric SIM Day will be held in March 2018

4.6 **Northern Ireland Update**

A Paediatric CLOD has been identified for N Ireland. The OD team was invited to a regional paediatric medical group looking at end of life and palliative care, this was very useful and has led to many further initiatives.

5. **Education and Training**

5.1 **Medical Education Training**

Members were informed that two National CLODs for an education and training position have been appointed, these are Dr Ben Ivory and Dr Dan Harvey. NHSBT are working on a medical education strategy, this will include addressing specific training in relation to paediatric and neonatal donation. Members are welcome to contact Jill Featherstone (Jill.Featherstone@nhsbt.nhs.uk), who is the PDS lead for medical education.

A Scales is involved in regular telecons with Jill and has agreed to liaise with S Steel to review the content of the SIM training modules. It was noted that taking this initiative forward will have financial implications, A Scales to feedback at next meeting. A Scales

6. Ongoing Work Streams

6.1 National Paediatric and Neonatal Strategy – Presentation Draft Strategy and Comments

A Scales presented a draft Paediatric and Neonatal donation strategy. 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 by 27th February 2018. K Hawkins to send a reminder of the deadline to the Committee. A Scales to circulate the first final draft to members by Friday 16th February.

A Scales /
K Hawkins / All

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 again advised to submit any project proposals to RINTAG for discussion and approval.

7.2 Information Sharing

Members felt that some of the correspondence sent to the committee distribution list may be relevant noted by the wider PICU community and emphasised the importance of sharing information more effectively. A Scales accentuated that each representative of the NODC Paediatric Committee is responsible for sharing any crucial information with their wider team. K Hawkins is happy to set up regular GoTo meetings for the team. Members are requested to liaise with K Hawkins to reach a consensus on this.

All

8. Next Meeting

8.1 The next NODC Paediatric Sub Group will take place on:
Wednesday 23rd May 2018, 11:00 – 15:00, Conference Room, Medical Society of London, Lettsom House, 11 Chandos St, Marylebone, London, W1G 9EB