

**MINUTES OF THE
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP
HELD ON WEDNESDAY 23RD MAY 2018**

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
Anthony Clarkson	(AC)	Assistant Director Organ Donation and Nursing, NHSBT
John Forsythe	(JF)	Medical Director, ODT
Jane Gill	(JG)	Co-Clinical Lead for Organ Donation, University Hospitals of Leicester
Neil Healy	(NH)	Specialist Nurse - Organ Donation, Scottish Representative NHSBT
Karen Healy	(KH)	Senior Case Studies and Communications Officer, NHSBT
Riaz Kayani	(RK)	CLOD and PICU Consultant, Addenbrookes Hospital, Cambridge
Chris Kidson	(CK)	CLOD Royal Hospital for Children, Glasgow
Debbie Macklam	(DM)	Senior Commissioning Manager, ODT, NHSBT, Leeds
Sue Madden	(SM)	Senior Statistician, NHSBT
Ajit Mahaveer	(AM)	Consultant Neonatologist, Central Manchester University Hospital
Nicky Matthews	(NM)	Specialist Nurse – Organ Donation, Oxford, deputising on behalf of Michael Griksaitis
Dawn McKimm	(DMc)	Team Manager, Northern Ireland Organ Donation Team
Reinout Mildner	(RM)	CLOD Birmingham Children's Hospital
Lumnije Mustafa	(LM)	Specialist Nurse - Organ Donation, North West Organ Donation Team
Naga Puppala	(NP)	CLOD and PICU Consultant, Alder Hey Children's Hospital
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation NHSBT
Simon Steel	(ST)	CLOD and PICU Consultant & Anaesthesia, Sheffield
Mick Stokes	(MS)	Head of Hub Operations, NHSBT
Hannah Bartlett Syree	(HBS)	Professional Development Specialist, NHSBT
Andre Vercueil	(AV)	Regional CLOD – London, deputising on behalf of Dale Gardiner
Carli Whittaker	(CW)	Paediatric Intensive Care Society (PICS) Nurse Representative
Joanna Wright	(JW)	Consultant Neonatologist, Leeds Teaching Hospital

IN ATTENDANCE:

Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT
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Item	Title
1.	Welcome, Introduction and Apologies
1.1	<p>K C Hawkins welcomed everyone to the meeting and noted the apologies given for this meeting. Apologies have been received from Aniko Deierl, Stephen Marks, Sally Holmes, Michelle Jardine, Yemi Jegede, Catherine Penrose, Nagarajan Muthialu, Stewart Reid, Teressa Tymkewycz, Caron Watts, Simon Raby, Simon Robinson, Michael Griksaitis, Chris Kearns, Caroline Davidson, Ella Poppitt, Margrid Schindler, Jon H Smith and Rachel Newton.</p> <p>Additional attendees were welcomed to the meeting: Dr Naga Kishore Puppola CL-OD, Alder Hey, Lume Mustafa, SN-OD NW region, Nicky Matthews, Specialist Nurse - Organ Donation, Oxford and Karen Healy - Senior Case Studies and Communications Officer</p>
2.	Review of previous minutes and action points
2.1	<p>The minutes from the last meeting were agreed as a true and accurate record of the meeting.</p> <p>Action Point 2- Care Plan A Scales has agreed to work with N Healy to adapt and tailor the current version of the Care Plan for our colleagues in Scotland. A meeting has been set up to take this forward.</p>

ACTION

Action Point 3 - EBK developments in < 2 yr. old donors

2019 meeting

An update will be provided in January 2019.

Action 5 - Chief Coroner Guidance

J Forsythe informed members that a first draft of the annual coroner report has been received and will be reviewed for any changes in the numbers following the publication of the Chief Coroner guidance. The final annual coroner report will be shared within this committee.

3. Matters arising**3.1 Banners and leaflets, electronic media**

A Scales noted that following the last meeting there had been some confusion about what was required. The NODC Paediatric group remains committed to taking this initiative forward, however with recognition that there are cost implications. Members suggested it would be encouraging and valuable to present some of the current electronic media on paediatrics at the National Organ Donation week in September. A Ttofa agreed to share current paediatric stories with the group to consider which stories should be included and shared at the national organ donation week. It was noted that a commissioning model is not currently in place and funding resources will need to be considered. A further update will be provided at the next meeting.

A Scales /
S Steel

A Ttofa

Add on agenda

3.2 Neurological Determination of Death Testing Forms

Ratification by RCPCH and BAPM remains in progress. Version 1 forms are available on the clinical website. Any updates, including updates to the 'adult' forms will be communicated to the committee in due course.

3.4 DCD donation under 1 month

A paper outlining Hepatocyte Only Donation in Infants less than 1 month old was submitted to ODT SMT for consideration. The proposal was agreed in principal and work is in progress reviewing how this will work operationally. A further update will be given at the next meeting.

A Scales

3.5 Information Sharing

Following previous discussions, it was felt that some of the correspondence sent to the committee distribution list may be noted by the wider team and emphasised the importance of sharing information more effectively. It was stressed that each representative of the NODC Paediatric Committee is responsible for sharing any information with their wider team.

K Hawkins offered to consider setting up regular GoTo meetings or explore Skype for business for the team but no feedback has been received from the committee to pursue this. A further update will be provided at the next meeting with a definitive action plan.

Add on agenda

4. NHSBT Behaviour Change Strategy

4.1 A presentation was received from A Ttofa outlining the NHSBT Behaviour Change Strategy. Please refer to the presentation. A Ttofa reminded members of a "Gift of Life" leaflet produced last year end requested that members circulate these leaflets within their paediatric intensive care units.

4.2 Neurological Determination of death video launch

K Hawkins presented the launch for the paediatric section of the neurological determination of death resources, showcased trailers of educational videos created by NHS Blood and Transplant for the determination of death by neurological criteria in infants less than 2 months old and for infants older than 2 months to 17 years of age, these resources are available on the ODT clinical website. Feedback from the committee was sought on how these videos can be shared and used within the Paediatric community.

It was suggested to share these at M&M meeting and include a link on the Paediatric intensive care (PICs) website. C Whittaker agreed to contact PICS webmaster.

4.3 **National Paediatric and Neonatal Strategy Update**

The consultation period for the strategy is now completed, comments received were positive, encouraging and constructive. A final version will be submitted to SMT with final approval being sought at the Board meeting in July. A final version will be circulated within the NODC Paediatric Committee. A Scales informed members that the format of the next NODC Paediatric meeting is anticipated to be a Workshop to identify and establish a workplan towards the new National Paediatric and Neonatal strategy.

5 **Media Update**

A Scales gave an update on behalf of Rachel Newton.

Death of Charlie Douthwaite, the baby who received a heart transplant at the Freeman in December 2017

An update was provided at the January meeting on the media interest in the case of Charlie Douthwaite who was listed for heart transplant at just six weeks old. When his story was picked up by the media we confirmed he was the youngest child in the UK waiting for a heart. Charlie went on to receive a transplant just before Christmas. Charlie sadly died on March 27th. Following his death, we supported the Freeman on their response to media and issued a statement expressing our condolences and acknowledging the precious gift from his donor's family.

BBC2 documentary - Heart Transplant: A Chance to Live

This documentary broadcast last week followed the heart transplant team at the Freeman and seven patients on the heart waiting list including two paediatric patients: an eight-month-old baby and nine-year-old Max Johnson, the boy who became the face of the Mirror newspapers opt-out campaign.

The Media & PR team was closely involved with the development of the documentary, supporting the production team over many months. The show was well received and, with social media support from ourselves on the day of broadcast, generated 1,100 ODR registrations in the first 40 minutes of the 90-minute length.

The total number of ODR registrations between 8pm and midnight was 3,172, compared with 539 the previous Monday - a near 500% increase.

Heart valve donation – paediatric case study

Media activity is planned for the coming weeks around heart valve donation to support the Eye and Tissue Strategy. This will feature the case study of a child who died in 2015 and helped two other children through heart valve donation. Members wished for the Eye and Tissue Strategy to be shared within this committee.

5.1 **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 few models have been explored reviewing data collation and how this can be utilised within the NICUs. A meeting took place reviewing PDA data and the content available on the BadgerNet platform. Comparison between datasets posed further questions for BadgerNet to consider and ensure the content is feasible to be published on the BadgerNet portal. Members raised concerns on the quality of data available on BadgerNet. Cost implications for this will require consideration. A further update will be provided at the next meeting.

Devolved Administration Updates:**5.2 Scotland update**

Data has been captured within units in Scotland on potential and actual organ donors via the Potential Donor Audit (PDA) and have had 11 referrals from neonatal units.

J Brierly informed members that a Steering group was established to explore national and international evidence on the clinical effectiveness and clinical/ patient/ lay attitudes towards ante-mortem interventions. NHSBT have agreed to work with the relevant professional organisations to develop new guidance. It was noted that Scotland would reconsider the guidance in their proposed new legislation regarding organ donation. The ICS and FICM have agreed to participate in this work. This item will remain on the agenda as a standing agenda item.

5.3 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.

M Jardine provided a written update informing members:

- The Paediatric Intensive Care unit have managed to increase SNOD presence
- The first paediatric organ donation simulation day will run in Wales on 27th May.
- Undergoing PDA in neonates and have some engagement from the Neonatal consultants.
- First DCD donation on PICU end November. A meeting is planned between PICU consultants and SNODs to facilitate joint working.

5.4 Northern Ireland Update

A Paediatric CLOD has been appointed 0.5PA for Northern Ireland. A neonatal referral last year did not proceed but led to a very positive experience, many educational opportunities. The OD team have been asked to present at a Regional neonatal conference and invited to join a regional group looking at an end of life and palliative care pathways. An increase in referrals rates has been noted within the PICU and continue to improve collaborative working with SNODS. Awaiting results from Northern Ireland consultation about taking organ donation forward with a remit of incorporating education resources for schools and medical students.

5.5 Education Strategy – Update

Members were informed that two National Education CLODs have been appointed as discussed at the last meeting, these are Dr Ben Ivory and Dr Dan Harvey. Work is in progress re developing the national deceased donation course to run 6 times a year with the aim of capturing all ICM trainees and new consultants. B Ivory and J Featherstone have attended the Paediatric SIM course in Bristol to develop understanding and consider how Paediatric simulation courses can be supported. S Steel will liaise with H Bartlett Syree regarding observing the Sheffield course. There was general agreement that a standardised course and content for paediatrics would be the way forward, and this work is likely to sit alongside the Paediatric Strategy. H Bartlett Syree extended the invitation for those interested to book places at the national sim course: 11/12 September Nottingham, 8/9 October St Georges.

Work is ongoing with the education team to redevelop the generic CLOD and Chair inductions programmes, streamlining and ensuring the content is standardised. H Bartlett Syree explained that they are in early stages at looking at developing on line education on the ODT clinical website.

6. Any Other Business

6.1 Psychological Impact of Paediatric Organ Donation

In absence of M Griksaitis, N Matthews highlighted an interest in considering psychological impact of child death for the multidisciplinary team in Southampton Paediatric ICU. In the past research has been conducted looking at symptoms of post-traumatic stress and moral distress in PICU. A medical student has worked with M Griksaitis to replicate this work looking at the impact of child death when organ donation is also involved. The preliminary data is showing when donation is involved there is significantly less incidence of post-traumatic stress symptoms but showed a higher incident of moral distress. It was noted that the data will be presented at conferences with a remit of replicating this nationally.

J Forsythe informed members that Rachel Stoddard-Murden (SNOD team manager) has had keen interest in this area and has submitted a proposal to develop an understanding of the psychological impact of deceased organ donation on frontline professionals in NHSBT. An application has been made for funding. Members encouraged and supported this initiative. J Brierley has a link to some PICs research and will send the details of this to M Griksaitis.

J Brierley

6.2 GDPR Compliance

A Ttofa requested members remove and discard any old leaflets and order new ones through the leaflet website to ensure GDPR compliance.

6.3 Replacement Rep Neonatal Nurses Association

Caron Watts is due to retire imminently and a replacement representative will be sought in due course.

6.4 Potential Donor Audit

S Madden reported that funding is now released to review the PDA dataset, it is anticipated to review, develop and deliver this within this financial year. It is crucial that there is paediatric consideration when collecting data in the future. This will be discussed at the next NODC meeting on 5th June with input from CLOD and regional CLODs.

A Mahaveer to be invited at the next NODC meeting.

A Iqbal

6.5 Kay's Retirement

K Hawkins thanked NODC Paediatric members for their support during her time as National Paediatric CLOD and Chair of Paediatric NODC. On behalf of NHSBT and NODC Paediatric committee, J Forsythe paid tribute to the outstanding contribution made by Kay Hawkins during her time as Chair of NODC Paediatric Sub Group and wished her well for the future.

7. Next Meeting

7.1 The next NODC Paediatric Sub Group will take place on:
Wednesday 26th September, 11:00 – 15:00, The Birmingham Conference & Events Centre, Holiday Inn, Hill Street, Birmingham, West Midlands, B5 4EW