

**MINUTES OF THE  
NATIONAL ORGAN DONATION COMMITTEE (NODC) PAEDIATRIC SUB GROUP  
HELD ON WEDNESDAY 12<sup>th</sup> FEBRUARY 2020**

**COPTHORNE HOTEL BIRMINGHAM, PARADISE CIRCUS, B3 3HJ**

**PRESENT:**

Reinout Mildner	(RM)	Chair, National Paediatric CLOD, PNODC Chair and PICU Consultant Birmingham Children's Hospital
Roxy Afzal	(RA)	Trainee Advanced Neonatal Nurse Practitioner, Manchester
Hannah Bartlett Syree	(HBS)	Team Manager, South Central ODT Team, NHSBT
Cherry Brown	(CB)	Senior Communications Officer – Media and PR, NHSBT
Chloe Brown	(CB)	Senior Statistician, NHSBT
Jan Bengtsson	(JB)	Consultant Paediatric Intensivist and CLOD Newcastle
Ben Cole	(CB)	Lead Nurse – Family Aftercare, ODT, NHSBT
Sue Duncalf	(SD)	Interim Head of Operations ODT, NHSBT
Dale Gardiner	(DG)	National CLOD, NHSBT
Jill Featherstone	(JF)	National Professional Development Specialist, Medical Education Lead, NHSBT
Louise Leven	(LL)	Neonatologist and CLOD Glasgow
Mairi Mackenzie	(MM)	Specialist Nurse - Organ Donation, NHSBT (Deputy for Susan Archibald, Scotland)
Alex Mancini	(AM)	Pan London Lead Nurse for Neonatal Palliative Care
Julie Menzies	(JM)	PICS Nurse representative (Deputising for Carli Whittaker, PICS)
Dawn McKimm	(DM)	Team Manager Northern Ireland, ODT, NHSBT
Catherine Penrose	(CP)	Paediatric CLOD, PICU Consultant, Leeds General Infirmary
Stewart Reid	(SR)	Paediatric CLOD, PICU Consultant & Anaesthesia, Belfast
Angie Scales	(AS)	Lead Nurse: Paediatric and Neonatal Donation and Transplantation NHSBT
Anju Singh	(AS)	Consultant Neonatologist, CLOD Birmingham Women's and Children's NHS Foundation Trust
Jon H Smith	(JHS)	Paediatric CT Anaesthesia / ECMO, Freeman Hospital
Fiona Wellington	(FW)	Interim Assistant Director - Organ Donation and Nursing, ODT, NHS Blood and Transplant
Joanna Wright	(JW)	Consultant Neonatologist, Leeds Teaching Hospital

**IN ATTENDANCE:**

Ambreen Iqbal	(AI)	Clinical & Support Services, NHSBT
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Item	Title
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**1. Welcome, Introduction and Apologies**

- 1.1 R Mildner welcomed everyone to the meeting and noted the apologies given for this meeting. Apologies have been received from John Forsythe, Joe Brierley, Omer Aziz, Jan Dudley, Caroline Davison, Michele Jardine, Ajit Mahaveer, Nagarajan Muthialu, Susan Archibald, Anthony Clarkson, Jane Gill, James Fraser, Michael Griksaitis, Yemi Jegede, Riaz Kayani, Chris Kidson, Stephen Marks, Sue Madden, Simon Steel, Debbie McGuckin, Teresa Tymkewycz and Carli Whittaker

Additional attendee was welcomed to the meeting: Roxy Afzal

**ACTION****2. Review of previous minutes and action points**

- 2.1 The minutes of the previous meeting were accepted as a true and accurate record of the meeting. All actions have either been completed or appear on the agenda.

### 3. Matters arising

#### 3.1 Neurological Determination of Death Testing Forms

Following discussion at the last meeting, the Neurological Determination of Death Testing forms have been updated and are awaiting approval from the Royal College of Paediatrics and Child Health. The approved version will be available for this Committee to use. It is anticipated that uniformity will be achieved in both the Adult and Paediatric guidelines.

#### 3.2 Coroner Update

R Mildner has discussed this with Professor Forsythe and recognises the need to re-engage with the Chief Coroner about the persisting increase in Coroner / Procurator Fiscal refusal rate for paediatric organ donation. This is an ongoing discussion and further update will be given in due course.

An outstanding action arising from the last meeting was for J Brierley to liaise with paediatric forensic pathologists, an update will be provided at the next meeting.

J Brierley

R Mildner informed members that London and South East have requested a meeting to enable regional teams to liaise with Coroner Pathologist and the Police to consider establishing a working relationship and address the protocols required to support the donation procedure. Y Jegede will update at the next meeting.

J Jegede

C Penrose gave a presentation which looked at the work Yorkshire have done locally to improve relationships and the process in relation to Pathologist, Police and Paediatricians. Please see presentation of slide for more information.

The following aspects were highlighted

- 1- Misunderstanding and misconception which can be reasonably resolved with just discussion.
- 2- Consideration of requests in relation to evidence gathering i.e. having a photographer present or pathologist present at the retrieval
- 3- Concerns regarding suspected homicide whereby the coroner will object to organ donation as this may compromise any criminal investigation.

It was stressed that a blueprint should be created which will improve the process, this could be incorporated into the national pathway.

It was noted that in 2019, 75% potential DBD in paediatric potential donors were declined by coroner and procurator fiscal.

#### **POD PPP update (Paediatric Organ Donation from Paediatric Units: Investigating Potential, Practice, Preferences and Perceptions)**

The current bid to secure funding remains with the NIHR, no final decision has been agreed to date. A further update will be provided.

#### **Performance Report**

Work is still ongoing, and an agreed performance report will be available to share with this Committee in the autumn.

### 4 PNODEC Membership and Terms of Reference - NODC PSG(20)1

#### 4.1 The amendments suggested at the last meeting have now been incorporated and members received a final draft of the membership list and Terms of Reference for information.

R Mildner highlighted the need to ensure that representation from each region is achieved to enable effective delivery of the strategic plan. It was noted that only one representative for a region attends this meeting, and the regional representative is accountable for sending a deputy where required.

Following discussion, there was consensus to alternate the NODC Paediatric meeting between a face to face and Skype call meeting. Members agreed that the February 2021 meeting will be facilitated via Skype and this change may be perceived as a financial cost saving exercise. Considering low attendance and minimal representation from the regional teams, it was agreed to monitor this and prompt members of the Terms of Reference.

A Scales informed members that seeking a Lay member representation is in progress and it was agreed to invite existing lay members of the main NODC committee to attend the Paediatric meetings.

Members acknowledged the importance of engaging with Palliative care representatives to complete some of the work with end of life care processes.  
The final ratified ToR will be circulated for information.

A Scales

## **5 Paediatric SNOD regional role description - NODC PSG(20)2**

5.1 A paper prepared and presented by A Scales was received.

The role description was ratified at a recent operational and regional managers meeting; this paper will then be further submitted to the Regional teams for final approval. It was recommended to add date of review and version reference on this paper.

A Scales

F Wellington suggested to set up a Skype meeting to discuss the Paediatric SNOD regional role description with representation from each of the 12 regional teams. This was agreed and invites will be sent.

## **6 Length of the donation process in PICU NODC PSG(20)3**

6.1 A six-monthly report was received outlining the length of the deceased paediatric organ donation and transplantation process. Over the course of last year, several pilots were run in four Trusts focusing explicitly at the length of process with the commitment to reverse the trend of organ retrieval being a daytime activity and organ transplantation being a night - time activity.

Members are asked to feedback and suggest any other measures which should be incorporated into the existing report.

All

F Wellington informed members of a recent meeting which took place to discuss feedback and findings from those pilots. Most delays were in relation to cardiothoracic offering (organs being accepted then declined at the last-minute causing delays).

Following in-depth discussion, members recognised the need to impose a strict time frame for acceptance times and suggested that the operational group consider an optimal time.

## **7 'Winston Churchill Memorial Trust Project' (Neonatal Organ Donation)**

7.1 R Afzal - Trainee Advanced Neonatal Nurse Practitioner shared her experience of gaining a Winston Churchill Memorial Trust Project fellowship. The Fellowships were set up in memory of Winston Churchill and are designed to encourage British citizens to learn from practices in other countries and pro-actively share their findings. R Afzal proposal was to visit places where NICU and OPO professionals had experience of carrying out Neonatal Organ Donation or had protocols / policies / training in place to support Neonatal Organ Donation. Please see presentation slides for further information.

## **8 Result of parent/guardian survey of attitudes towards deceased organ donation**

8.1 Deferred to the next meeting for an update.

## **9 Regional Feedback**

### **9.1 Scotland**

A summary of the neonatal potential donor audit between 2016 – 2020 was noted. Scotland currently have 8 level 3 neonatal units. It was reported that around 80-92% of cases each year are from RHC Glasgow and Edinburgh.

Following a lesson learned exercise, it was reported that all the NICU units are engaging well with the audits, but the referral rate remains static.

### **Yorkshire**

The Yorkshire Organ Donation Services Team are undergoing various organ donation promotional campaigns, such as Be a Hero. Concerns were raised about poor SNOD representation within the unit which subsequently has an impact on the nursing interface.

C Penrose was requested to give a lecture at the Royal College of Anaesthetists and is also invited by the Paediatric and Neonatal national pharmacy group to give a lecture on organ donation at a Conference in the Summer 2020.

**South Wales**

No representative present from South Wales.

**South West**

A Scales reported on O Aziz's behalf, O Aziz is the Paediatric CLOD for Bristol on BAME communities and promoting organ donation. The South West team have been very proactive, and O Aziz is a member of the faculty for the new paediatric leadership course. Following a case in Truro, a guidance document is being prepared for paediatric donation in local district general hospitals.

**South East/ London** – No representative present.

A Scales reported a regional action will be in place highlighting points in conjunction to the recommendation following a recent collaborative meeting. This meeting was attended by clinical leads and various professional bodies from all PICU units in both South East and London. A Scales to request an update for the next meeting.

A Scales

**Northern Ireland**

Currently trying to further establish collaboration with Paediatric SNOD. T Price has joined as a full time Paediatric SNOD who is attached to the PICU in Belfast. PICU capacity remains a challenging issue in their children hospital.

A Scales informed members of enquiries received from the Health and Social board commissioning team specifically around neonatal donation in Northern Ireland.

D McKimm informed members of a simulation training event which is imminent. Following changes in the legislation an organ donation manager will be appointed to work with schools to raise awareness. The interview and selection for this is complete.

**North west**

No representative present

**Eastern**

No representative present.

**South Central**

A paediatric CLOD in Oxford will be appointed in the near future.

**Northern**

J Bengtsson continues to work with the local SNOD team to understand the challenges faced in the Northern region.

**Midlands**

Dr Anju Singh (Consultant neonatologist) is appointed as the CLOD at Birmingham Women's and Children's Hospital.

In light of the low attendance levels and lack of representation from some regions, members agreed for this be monitored and addressed as required.

**10 Media Plan**

10.1 C Brown gave a comprehensive media update detailing recent, current and future projects.

**World Heart Day activity**

At the end of September there was a week of activity initially focusing on the overall need for paediatric hearts. Coverage included front page of the Sunday Mirror, Sunday Express spread and BBC Breakfast and social media outlets.

**Christmas Campaign**

In early December press releases were sent out nationally and regionally with figures about the number of people facing Christmas waiting for a transplant, including children.

Case studies of children waiting for hearts were used proactively to highlight the fact there is a need for young donors, and that children can save lives too.

There continues to be interest in neonatal donation, A Scales has published an opinion piece for Infant Journal and BBC Breakfast aired a piece around neonatal organ and tissue donation – where donors are aged 0-28 days old – on Friday (7 Feb). Anthony Clarkson participated in a live studio interview. This resulted after NHS England did a Twitter takeover and a neonatal nurse called, shared the story of an 8-day old baby boy, who died and donated tissue in 2016. This very powerful and emotive thread was very well received, and the BBC contacted set up interviews for BBC Breakfast (pre-recorded) and BBC News website.

A Scales and the Clinical statistics department worked together to provide figures on neonatal donation. There have been 40 neonatal donors between 2009 and 2019.

### **Forthcoming releases**

A CBBC documentary is due to be shown on Tuesday 18th February, following a boy called Jack who was waiting for a heart for over a year and received a transplant last Spring. This has been led by the production company and the Freeman Hospital and is in Jack's own words which has a powerful impact. NHST have been supporting the donor family, the donor was a child.

### **World Kidney Day - March**

NHSBT will be highlighting deceased kidney donation and tying this into the law change, there will be a living donation element. There may be paediatric opportunities. The campaign will coincide with World Kidney Day which takes place on Thursday 12 March and a week of activity will take place.

### **Order of St John ceremonies (April until autumn)**

The awards to donor families will be publicised as normal but hoping to focus more on paediatric stories – spread across the year with a range of coverage.

### **Law change**

A Scales and C Brown continue to work to raise the profile of children as an excluded group, this is likely to be after the law is implemented.

### **Social Media family contact**

Concerns were raised around challenges whereby recipient families have directly contacted donor families on social media. It is suggested to draw up strict guidelines for both the donation and recipient side, reinforcing the message and limit information sharing on social media. This is to protect anonymity and the wellbeing of all families. A Scales to liaise with the lead recipient coordinator lead K Morley about this. B Cole is also working with the DRD to support donor families.

A Scales

## **11 RAG rating for Strategy – NODC PSG(20)4**

- 11.1 A Scales presented the Red, Amber and Green (RAG) rating action plan. The rating tool will act as a framework for identifying high priority areas and actions within the strategy. Most of the actions have a year timeframe. It was reported that the change in legislation had an impact on the timings of completion for some of the actions. A further update will be provided at the next meeting.

A Scales

## **12 Strategic plan – Workstream Progress**

- 12.1 A Scales provided members with an update and a presentation on the Strategic plan workstream. The statistical measures have all been agreed and are available online. The performance reporting matrix is still in progress and outstanding. Modification of national triggers for notification suggested, these have been agreed by R Mildner group and CLODs will discuss this with colleagues and feedback. The aim is to trial this in 3 regions initially London, Eastern and Yorkshire.

A Scales informed member that the Professional Development Team are keen to continue supporting the multidisciplinary leadership course in Child and Infant Deceased Donation.

The first course has been delivered and future dates have been planned. Course content will be continuously reviewed and updated. The course is aimed at:

- CLODs covering PICUs
- Paediatric Regional Lead SNODs
- SNODs covering PICUs
- Specialist Requestors
- Family liaison staff in PICUs

Forthcoming dates:

**March 24th, 2020 in Bristol**

### **Specialist requestor training and support**

The education workstream is continuing to review how paediatric specific information can be incorporated. A Scales liaised with South Central and Midlands and have agreed to draw together some guidance around supporting bereaved children of adult donors. Following the Yorkshire model, A Scales briefed members about the ongoing discussion around Hospice support post donation. The proposal is for regional teams to explore this possibility with regional hospices.

Work stream updates will be provided at every meeting. Please see Workstream Presentation slides attached.

### **13 DCD hearts for paediatric donor and recipients - NODC PSG(20)5**

- 13.1 A Joint Innovation Fund (JIF) has been provided by NHSE and NHSBT. The JIF is an interim fund for a maximum of 3 years (or until the fund is used) with initial approval for DCD hearts for 12 months. Whilst there is no guarantee of any additional funding at the end of the JIF, it is hoped that the costs of consumables will decrease sufficiently to allow the business case to be re-submitted.

Papworth continue to work alongside NHSBT to approve their modified mOrgan machine for clinical use with the aim to support DCD heart retrieval from children and smaller infants subject to specific research and MHRA approval.

It was noted that Great Ormond Street Hospital transplanted their first DCD heart into a paediatric recipient.

### **14. Any Other Business**

#### **14.1 JPAC Guidance update**

A Scales advised that in the past heart valves have been declined from children due to the use of cold rooms and cooling cots / blankets. An amendment of the word "refrigeration" to other cooling methods within the JPAC guidance has been requested and agreed. JPAC guidance is a joint UKBTS professional advisory committee who provide guidance on suitability around usage of tissue. The guidance update will appear in the next published edition. A Scales to share guidance website link, once this change is endorsed.

A Mancini announced the publication of a textbook for nurses in Neonatal Palliative Care. This holds a chapter on organ and tissue donation in neonates written by A Scales.

The Chair noted this was the last meeting for S Steel and D McKimm and thanked both for all their commitment and work over the years and wished them well in the future.

### **15. Next Meeting**

- 15.1 The next NODC Paediatric Subgroup will take place on Wednesday 23 September 2020, 11:00 – 14:00 via Microsoft Teams Meeting.