

# European Neonatal Ethics Conference – 2019

## “Sharing Ethical Practice Together”

**November 14<sup>th</sup> and 15<sup>th</sup> 2019**

### **Venue:**

**St Mary's Stadium Road,  
Southampton,  
SO14 5FP**



### **Speakers**

**Professor Keith Barrington**

Professor of Paediatrics, University of Montreal, Quebec Canada

**Professor Felicity Boardman**

Associate Professor, Warwick Medical School

**Dr Sonia Carbonero**

Associate Professor of Paediatrics, Hospital Rio Hortega  
Valladolid Spain

**Dr Claire Boithias**

Consultant Neonatologist Paris University Hospitals, Paris,  
France

**Dr Rosa Geurtzen**

Fellow in Neonatology and Neonatal Research, Radboud  
University, Amalia Children's Hospital, Netherlands

**Dr Annie Janvier**

Associate Professor Department of Paediatrics Consultant  
Neonatologist & Ethicist, University of Montreal, Quebec,  
Canada

**Lisa Leppard**

Senior Sister Lead Family Care, NICU, Princess Anne Hospital,  
Southampton

**Professor Hugo Lagercrantz**

Emeritus Professor Karolinska Institute Stockholm Sweden

**Dr Joanna Wright**

Consultant Neonatologist Leeds UK

**Professor Neil Marlow**

Professor of Neonatal Medicine, UCL, London, UK  
Ex-President European Society of Pediatric Research

**Dr Trisha Prentice**

Consultant Neonates & Bioethicist, Royal Children's Hospital  
Melbourne Australia

**Mr Robert Wheeler**

Consultant Paediatric Surgeon & Director Dept of Clinical Law  
University Hospital Southampton

**Professor Claudia Wiesemann**

Director Department for Medical Ethics, Gottingen  
University Germany

**Professor Fiona Woollard**

Professor of Philosophy, University of Southampton

## Professor Dominic Wilkinson, Chair, European Neonatal Ethics Conference



Dominic Wilkinson is Director of Medical Ethics and Professor of Medical Ethics at the Oxford Uehiro Centre for Practical Ethics, University of Oxford. He is a consultant in newborn intensive care at the John Radcliffe Hospital, Oxford. He also holds a health practitioner research fellowship with the Wellcome Trust and is a senior research fellow at Jesus College Oxford. Dominic has published more than 120 academic articles relating to ethical issues in intensive care for adults, children and newborn infants. He is co-author (with Julian Savulescu) of 'Ethics, Conflict and Medical treatment for children, from disagreement to dissensus' (Elsevier, 2018). He is also the author of 'Death or Disability? The 'Carmentis Machine' and decision-making for critically ill children' (Oxford University Press 2013) ("the best book of the decade in bioethics... this is a book that must be read by everybody who is seriously interested in the bioethical issues that arise in neonatal intensive care or, more generally, in decision making for children with chronic, debilitating or life-threatening conditions." (John Lantos, Notre Dame Philosophical Reviews). He was Editor and Associate Editor of the Journal of Medical Ethics from 2011-2018. Twitter: @Neonataethics

## Dr Alok Sharma Co-Organiser and Treasurer European Neonatal Ethics Conference



Dr Alok Sharma is a Consultant Neonatologist at Princess Anne Hospital Southampton. He is Lead for the Wessex-Oxford Neonatal Education Programme. Alok started his postgraduate training in paediatrics in India completing an MD on 'Meconium Aspiration'. He has trained in neonatal and paediatric intensive care at Aberdeen, London, Exeter, Southampton and Leicester. He has founded the 'Neonatal Ethics and Difficult Situations Course' which is run nationally in multiple centres in the UK along with Dr D Wilkinson, Dr Sijo Francis, and Dr S Babarao. He has also developed the OPEN concept in simulated learning and worked on its implementation in ethics education. He has run numerous workshops on the ethical aspects of implementation of therapeutic hypothermia in India in partnership with the National Neonatology Forum India. Work on multidisciplinary neonatal simulation done by his team, and its impact on neonatal outcomes was nominated for the National BMJ Award securing the Runner's Up position in 2014 and was awarded the Best Research Award at ASPIH 2014.

## Lisa Leppard Chair Scientific Committee



Lisa Leppard is a Senior Sister/ Family Care Sister on the Neonatal Unit at Princess Anne Hospital Southampton UK. She has worked on the Unit for 27 years and has developed the role of Family Care Sister. She has been instrumental in leading the team to achieve Bliss Baby Charter Accreditation for the unit. Lisa leads the Family Care Team in Southampton, counselling & supporting parents throughout their stay on the Neonatal Unit and is also the nursing palliative care lead for the Thames Valley and Wessex Neonatal Network and co-authored the Network Palliative Care Guidelines. She has trained as a Gestalt /Humanistic counsellor and is devolving a counselling service within the Neonatal Unit for parents. She is currently working the UHS psychology team to implement a Mental Health Frame work for parents on NICU. Lisa joined the NEDS team in 2014 and has helped support delivery of the courses in Southampton and London. This involves simulated scenarios in neonatal ethics, brain death and organ donation. Lisa recently qualified as an accredited Mediator and hopes to expand her role in this area soon.

## Dr Jasim Shihab Treasurer & Co Organiser



Dr Jasim Shihab is a Consultant Neonatologist working at East Lancashire NHS Trust . He has completed training in Neonatology in India, Aberdeen and London. He has also completed training in Neonatal Transport with the NETS team. He is an accredited neonatal simulation instructor with the MPROvE Academy since 2015 and has been instrumental in setting up the 'Difficult Neonatal Airway Course'.

Jasim's area of special interest in 'Impact of Culture' on Performance amongst trainees during communication. He has run simulation workshops on this with the MPROvE Academy both in the United Kingdom, and overseas. He is also involved in research on the use of death as a modality of training in neonatal simulation.

# EUROPEAN NEONATAL ETHICS CONFERENCE 2019

## Programme



Day 1  
St Mary's Stadium Southampton UK

## Programme

0730-0900

**REGISTRATION (Foyer Entrance) Please bring your eventbee ticket with you (*Tea & Coffee Press Room*)**



0900-1100

**MAIN CONFERENCE -MIKE CHANNON SUITE**



### SESSION 1 COMMUNICATION

***Chair-Sijo Francis***

0900-0930

Communication around end of life care for neonates

Do current frameworks work, or do we need change?

**Lisa Leppard**

0930-1000

How should we be communicating with families when making difficult decisions about their babies

What research tells us?

**Neil Marlow**

1000-1030

Integrating parental voices in Neonatology

**Annie Janvier**

1030-1100

*Tea & Coffee Press Room*



1100-1200

**SESSION 2 COMMUNICATION IN DIVERSE CIRCUMSTANCES \*Workshops**

**\*3 themes participants can attend any one workshop**



**Matt Le Tissier Suite**

**Religion vs Futility**

How should we approach shared care in a setting of religious disagreement. While Alok, Jasim and Sharon will help you through this, Barrister Mr Wheeler will address what happens when cases go to court



**Mike Channon Suite**

**Personalised Prenatal Consultation**

Communication has moved from provision of information in a standardised neutral way to a more consultative approach. Hear Annie and Keith take you through a different more personalised approach



**Presidents Suite**

**Letting my baby die who's decision**

When stopping life sustaining intensive care is it fair to let parents make the decision or should multiprofessional teams decide. Lisa, Karen and Sijo will take you through whether there is a middle ground

1200-1300 Lunch Mike Channon Suite \*Please note this will be a fork buffet

Poster Walk and Short Oral Presentations start at 1245 till 1330 in the Press Room

1330-1430

### SESSION 3 PALLIATIVE CARE (3 Themes Participants Attend 1 workshop)



**Presidents Suite**



**Mike Channon Suite**



**Matt Le Tessier Suite**

#### Moral Distress on the NICU

What do staff do if they feel constrained to look after babies in opposition to their ethical beliefs or disagree with parents regarding best interests of the child. What do we do when we think babies are suffering and we can't keep them comfortable? How do staff deal with moral and ethical dilemmas while continuing to care? Trisha and Lisa will be running a workshop on these issues.

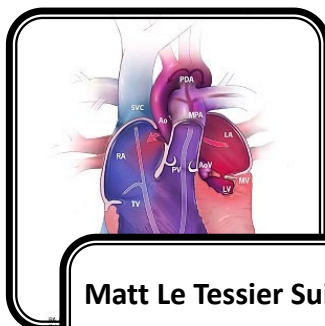
#### International Perspectives

Rosa \*Netherlands will be talking about antenatal counselling at extremes of prematurity from a Dutch perspective while Claire \*France will be talking about antenatal decision making from a French perspective. This will be followed by a panel discussion with Dominic, Rosa, and Claire as chairs.

#### Limiting Nutrition in Neonates

Alok, Karen, Sharon and Sijo will explore your feelings regarding limiting nutrition as part of neonatal palliative care. Where should we be using it as a treatment choice, and in which babies. What if it's not working. How is it practiced in different countries? Do we provide analgesia? What if it's not working

### 1430-1530 SESSION 4 HOT TOPICS ROUND TABLE CASE PRESENTATIONS



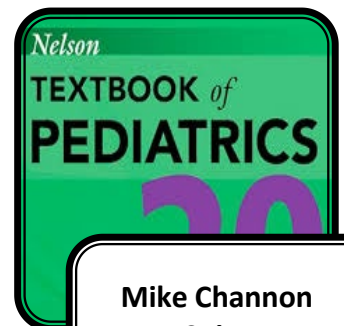
#### Matt Le Tessier Suite

"Variation of practice in counselling and interventions for hypoplastic left heart syndrome: what is acceptable?"

**Keith Barrington**



#### Presidents Suite Abstracts



#### Mike Channon Suite

Managing Trisomy 13/18 Not what the book said!!

**Annie Janvier**

*Abstract Presentations Mike Channon Suite Chair Jasim Shihab*

*Surrogacy and the Critically Unwell Neonate: Where are we in the UK? **Mona Noureldine ST5 Royal Wolverhampton NHS Trust UK***

*Treatment of ultra-rare neonatal diseases with expensive medication in a publicly funded health care system: challenges and opportunities **Martin Offringa Consultant Neonatologist, The Hospital for Sick Children, Toronto, Canada***

*Palliative tracheostomies in infants with life-limiting conditions **Anne Bean ST8 Neonates St Marys Hospital Manchester UK***

*The end at the beginning: consideration of end of life decision making in ventilator independent neonates with ultrashort gut syndrome **Jennifer Peterson ST5 St Marys Hospital Manchester UK***

1530-1600 Tea & Coffee Press Room

1600-1745 **Session 5 Plenary Sessions Mike Channon Room**

1600-1700 **Plenary 1**

**Resuscitation at Extremes of Viability-Current Evidence & Practice**

Chair-**Professor Dominic Wilkinson**

Speaker 1 British Association of Perinatal Medicine Framework-**Neil Marlow**

Speaker 2 Canadian Neonatal Network Guidance- **Keith Barrington**

1700-1745 **Plenary 2**

**Foetal Ethics-When does the foetus become a human being with human rights**

Chair-**Dr Alok Sharma**

Speaker- **Professor Hugo Lagercrantz**

# EUROPEAN NEONATAL ETHICS CONFERENCE 2019

## Programme



Day 2  
St Mary's Stadium Southampton UK

## Programme

0730-0830

**REGISTRATION (Foyer and Entrance)** Please bring your eventbee ticket with you *Tea & Coffee Press Room*



0830-1100

**MAIN CONFERENCE -MIKE CHANNON SUITE**



### **SESSION 6 ETHICAL DILEMMAS IN NEONATAL CARE**

#### **Chair Dominic Wilkinson**

0830-0900

Futile tourism: should parents be permitted to take their child overseas for continued intensive care ?

**Dominic Wilkinson**

0900-0940

Do babies have a right to breast milk?

**Fiona Woollard**

0940-1020

Am a Boy or a Girl?

Sex and gender ambiguity: Ethical dilemmas in healthcare for infants and children with DSD/intersex

**Claudia Wiesemann**

1020-1100

“Impossible Decisions in Neonatal Care”

**Robert Wheeler**

1100-1130

Tea & Coffee Press Room



1130-1230 **SESSION 7a PARENTS PERSPECTIVE & \*Abstracts**

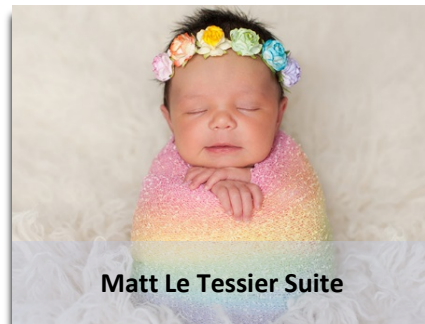
**\*3 themes participants can attend any one workshop**



**Neonatal Palliative Care**

**Abstracts 1-4 15 minutes each**

**Chair Hugo Langercrantz and Sijo Francis**



**Matt Le Tessier Suite**

**Rainbows and Storm clouds**

**How do parents cope with neonatal loss. How do they support others in the same position?**

**Anna Todorovic Dominic Wilkinson  
Lisa Leppard**



**Mike Channon Suite**

**Ethical Issues Limits of Viability**

**Abstracts 4-8 15 minutes each**

**Chair Alok Sharma and Jasim Shihab**

1. *Conflict associated with decisions on life-sustaining treatment in a neonatal intensive care unit at a tertiary hospital in South Korea*-**Dr Min Sun Kim, Seoul, Korea**
2. *Charlie's Law: Should the Justification for Withdrawal of Life-Sustaining Treatment for Children on the Intensive Care Unit be changed from Best Interests to Significant Harm?'* -**Dr Peta Coulson Smith, Southampton UK**
3. *End-of-Life Decisions 20 Years after EURONIC: Neonatologists' Self-Reported Practices, Attitudes, and Treatment Choices in Germany, Switzerland, and Austria* **Dr Katja Schneider, Berlin, Germany**
4. *"Quality of Life": Parental and neonatologist perspectives* **Shannon Adams, B Lechner Providence, USA**
5. *The collective burden of perinatal care in the 22<sup>nd</sup> week of gestation: Is the focus of contemporary ethical controversy misplaced?* **Dr C Carlos, Dr Naomi Lavalentha, Chicago, USA**
6. *All the small things: An exploration of hands-on care at threshold viability in Japan* **Dr Chantelle Tomlinson, Sheffield UK**
7. *Reviewing recordings of neonatal resuscitation with parents: the missing piece of the puzzle* **Dr M C Denboer**
8. *Counselling of Parents of Premature Babies. A novel approach* **Dr Zahreddin Abusalah, Dubai UAE**

1330-1410

## SESSION 7b PARENTS PERSPECTIVE

**\*3 themes participants can attend any one session**



**Presidents Suite**



**Mike Channon Suite**



**Matt Le Tessier Suite**

**Pete Sheppard**

**The Diary of an Anencephaly  
Father Preparing for life and  
death of my baby**

**Olivia Gordon**

**A little stranger: A mother's  
experience of genetic  
diagnosis in the NICU**

**Ali Le Povoidein**

**Being a neonatal nurse and  
mom to an extremely  
preterm baby**

1410-1520

## **SESSION 8 SCIENTIFIC SESSIONS**



**Matt Le Tissier Suite**



**Mike Channon Suite**



**Presidents Suite**

**Neonatal Death Debriefing vs  
Aftercare**

What is the perception of health professionals with regards to the support they receive and that should be in place after a baby dies? Does debriefing happen, work, how should it be done, who by, when, where, what should be discussed??

**Ethical Potpourri**

**Neonatal Organ Donation**

What is the current state of neonatal organ donation in Europe, what's happening where, Which organs are being donated, Why is there such a disparity around Europe, What are different countries trying to do to tackle this?

**Ethical Potpourri Chairs Prof Hugo Lagercrantz and Sijo Francis**

1. *End of life decisions and Ethical Issues in the NICU-Physician attitudes and self-reported practices in Greece* **Dr I Chatziioannidis, Athens, Greece**
2. *Evolving influences on the initiation of life-sustaining technology in children* **Dr Denise Alexander**
3. *Supporting Parental Decision-Making in the Neonatal ICU: The Experience of Moral Distress and 'Moral Schism'*-**Dr Rebecca Greenberg, Toronto, Canada**
4. *Moral distress arising from decision-making conflicts: how much should we accept?* **Dr Trisha Prentice, Melbourne Australia**

1520-1600

*Tea and Coffee Press Room*

**SESSION 8 PLENARY-**

**Mike Channon Suite Chair Dominic Wilkinson**

1600-1640

Whose life is worth preserving? The social and ethical consequences of prenatal screening and its impact on neonatology

**Felicity Boardman**

1640-1730

**The NICU Parent Panel** - \*Think of your questions!!!

This year at the ENEC 2019 we have a parent's panel consisting of parents, NICU nurses, NICU specialists, NICU consultants all of whom have had children having received care on the NICU. They will be part of a panel answering your questions. Think of a pertinent question you would like to ask them.

# SPONSORS AND EXHIBITORS





This meeting has been supported by the above organisations through the purchase of exhibition stand space only

# European Neonatal Ethics Conference

## Oral Case Presentations 14th November: Abstract

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**Mike Channon Suite 230pm to 345pm**  
**Instructions 15 minutes presentation time with 3 minutes for questions**  
**Award Category-Best Case Presentation**

**Submission by:**

Name: Mona Noureldein  
Institution: New Cross Hospital, Royal Wolverhampton NHS Trust  
Specialty & Year: ST5 Paediatrics  
Contact Address: Wolverhampton Rd, WV10 0QP, UK

email: mona.noureldein@nhs.net  
Mobile: 07459766084  
Wessex Trainee: No

**Submission for:** Both Podium and Poster if possible

**Title:** Surrogacy and the Critically Unwell Neonate: Where are we in the UK?

**Author(s):** Noureldein M, Chinthala D, Kagla M, Pillay T

**Abstract:**

**Introduction**

Under UK law, the surrogate mother has the right to keep the baby and surrogacy agreements are not legally binding. Parenthood is transferred by parental order or adoption.

**Aim**

We describe our dilemma in decision making in the potential re-orientation of care of a critically unwell newborn baby, whose surrogate mother was critically ill. We argue for clearer and standardised information on surrogacy agreements to be made available in such cases.

**Case report**

A term infant was born to a surrogate mother via emergency Caesarean section under general anaesthesia. The surrogate mother was noted to have ruptured her uterus. Baby was born in a poor condition, immediately offered full intensive care support. A diagnosis of severe hypoxic-ischaemic encephalopathy (HIE) was made, and the baby was offered total body cooling.

Our primary dilemma: Who carried parental responsibility to commence discussions around the possibility of reorientation of care? Medico-legally, it is the surrogate mother, but she was critically ill. The neonatal team was not aware of any antenatal surrogacy agreement addressing the specific scenario. Our Trust legal team confirmed: a) parental responsibility lies with the birth mother; b) intended father couldn't assume parental responsibility, c) the medicolegal decision on care lies with the attending physician.

On day 2, the surrogate mother recovered and registered the birth of the baby with the intended father present on day 3. At this stage, the intended father could assume parental responsibility. On day 5, the baby was extubated, but had poor neurological responses. Also, MRI confirmed radiological features in keeping with severe HIE.

As the intended parents lived in a different region, the baby's care needed to be transferred to another neonatal unit. Herein lay our second dilemma: we were now moving the baby away from the legal mother. The baby's condition was still such that any deterioration could result in a further decision for re-orientation of care. Under the guidance of the Trust legal team, the option to relinquish decision making solely to the intended father was

immediately accepted by the surrogate mother. Also, the intended parents and surrogate mother signed an advanced care plan and consent for transfer.

### **Conclusion**

Our experience highlights the importance of robust, transparent, and easily accessible antenatal agreements, together with clear national guidelines on what neonatal teams ought to be doing in complex situations such as in the case of critically unwell baby and surrogate mother.

**Submission by:**Name: **Martin Offringa, MD PhD**email: [martin.offringa@sickkids.ca](mailto:martin.offringa@sickkids.ca)Institution: **The Hospital for Sick Children, Toronto, ON, Canada**Mobile: **+1 416 452 8635**Specialty & Year: **Neonatology 1997**Wessex Trainee: **No**

Contact Address:

Room 11.9.720, Peter Gilgan Centre for Research and Learning  
The Hospital for Sick Children  
686 Bay Street, Toronto, Ontario, M5G 0A4, Canada

**Submission for: Podium**

**Title:** Treatment of ultra-rare neonatal diseases with expensive medication in a publicly funded health care system: challenges and opportunities.

**Author(s):** Martin Offringa, MD PhD, Jessica Faust, MSW, Randi Zlotnik Shaul, JD LL.M PhD, and Peter Kannu, MD PhD. (Neonatologist, Social worker, Paediatric Ethicist, Clinical Geneticist, respectively)

**Abstract:**

In this age of novel treatment approaches aiming to repair the mechanistic causes of disease, therapeutic choices need to be informed by more than just safety and efficacy considerations.

**Case history**

A term infant born to healthy non-consanguineous parents developed significant respiratory distress 12 hours after birth. A skeletal dysplasia was suspected because of the abnormal chest x-ray (thin ribs and metaphyseal long bone flaring) and physical examination (depressible skull bones and a bell-shaped chest). Serum ALP levels were undetectable. At age 3 days, perinatal hypophosphatasia (HPP) was diagnosed. A week later, it became clear that the neonate was completely ventilator dependent. Enzyme replacement therapy (ERT) for HPP had just been approved in our jurisdiction as a disease-modifying treatment.

**Ethical conundrum**

The medical team faced the decision of whether to commence and, if effective, maintain ERT. Published data on ERT for life-threatening HPP are from three small clinical trials reporting generally positive outcomes, but not for all. ERT's extreme cost (several hundred thousands of dollars per patient per year) and health insurance coverage uncertainty immediately created practical and ethical challenges: clinical uncertainty, transparency with parents, informed consent / shared decision making, resource allocation / justice, conflict of interest for clinician researchers, and "best interests" for the child.

The NICU team wrestled with determining what constituted patient benefit, defining a reasonable amount of time to realize benefit, and whether potential benefits outweighed ongoing harms. A bioethicist assisted in clarifying who determined the neonate's best interests and how to navigate potential conflicts of interest for treating physicians involved with prior clinical trials. We practiced a transparent model of shared decision-making with the parents. Parental expectations regarding potential outcomes and treatment limits were clarified upfront: ERT would be administered for a fixed period of time after which prospectively defined and agreed upon benefit and harm outcomes evaluated to inform ongoing decisions. A lack of a sustainable funding model for this particular ERT did not influence decision-making, however cost posed additional ethical considerations.

**Case outcome**

After a trial of several weeks with predefined criteria for clinical response, the team recommended ERT cessation, extubation, and comfort care. The parents agreed and the child passed away.

Here we highlight the ethical challenges of applying a shared decision-making model to start and stop an expensive new treatment for an ultra-rare disease in a publicly funded healthcare system when the medication's long-term effectiveness is unknown, offering some guidance.

## European Neonatal Ethics Conference Oral or Poster: Abstract Submission

*Please complete on one page, Arial font size 10. Abstract of no more than 400 words.  
Submission indicates consent for possible publication of this material on the WONEP website and the  
conference booklet. Please return as a word document by email to [mproveonline@gmail.com](mailto:mproveonline@gmail.com)  
Please read rules for abstract below*

### **Submission by:**

Name: Jennifer Peterson and Anne Bean

Institution: St Mary's Hospital, Manchester.

Speciality and Year: Neonates, ST5 and ST8.

Contact Address: Flat 19, The Slate Yard, 7 Stanley Street, Manchester. M3 5EX.

Email: [jennifer.peterson@hotmail.co.uk](mailto:jennifer.peterson@hotmail.co.uk)

Mobile: 07922864042

Wessex Trainee: No

**Submission for:** Both.

**Title:** Palliative tracheostomies in infants with life-limiting conditions.

**Author:** Dr J Peterson, Dr A Bean, Dr Ranganna Ranganath, Dr K Tanney

### **Abstract:**

The Universal Declaration of Human Rights (1948) legally introduced the concept that every human being has a set of rights that would be upheld in court. These rights were formally extended to children via the United Nations Convention of the Rights of the Child (1989). Articles 6 and 7 stipulate that 'every child has the inherent right to life', and the core principles of the Convention self-reportedly include, "devotion to the best interests of the child". The UK ratified this framework in 1991.

Whilst this right does not translate into keeping the child alive at all costs, it does imply an obligation to ensure all children have access to medical interventions that enable a meaningful life; even if that life is time limited. There are an increasing number of infants with conditions that confer an unstable airway or respiratory system, either structurally or functionally. These infants are often ventilated whilst being investigated. Some will never receive a diagnosis, meaning prognosis is very hard to define.

In our unit, three recent cases arguable aligned themselves well to palliative tracheostomy insertion, enabling the infant to be discharged with their family, facilitating meaningful memories to be made. However, there is an understandable trepidation around performing 'palliative' tracheostomy, as it offers the option for ventilation during future episodes of deterioration, sustaining life substantially and increasing the burden on already overwhelmed intensive care services.

Due to the difficulties described, our three babies have had very different outcomes one infant received a palliative tracheostomy and is currently in discharge planning to go home; another very sadly died before this could be explored to a significant extent and the other remains an inpatient on the NICU, currently dependent on continuous positive pressure ventilation via an endotracheal tube with very limited quality of life.

We argue that, for babies and families where tracheostomy would facilitate an improvement in quality of life (even if short) this is a viable management option, and services should evolve to fit the need of our ever-changing neonatal population.

In addition, we feel a similar line of argument to the double-effect doctrine would apply. If invasive ventilation is not felt to be in the infant's best interests, the complexities of care should be explored with families prior to tracheostomy formation and discharge, ideally with the aid of community and palliative care teams and the use of thorough Advanced Care Planning.

## European Neonatal Ethics Conference Abstract Submission 2019

Submission by: Jennifer Peterson  
Institution: St Mary's Neonatal Intensive Care Unit, Manchester.  
Speciality and Year: Neonates ST5  
Contact Address: Flat 19, The Slate Yard, 7 Stanley Street, Manchester. M3 5EX.  
Email: [jennifer.peterson@hotmail.co.uk](mailto:jennifer.peterson@hotmail.co.uk)  
Mobile: 07922864042  
Wessex Trainee: No

Submission for: Both

**Title: The end at the beginning: consideration of end of life decision making in ventilator independent neonates with ultrashort gut syndrome**

**Author:** Dr J Peterson

### **Abstract:**

A was born at term with an antenatal diagnosis of gastroschisis. His parents were well informed about the condition and understood that he would require surgery. However, at delivery his bowel was found to be severely compromised. A returned from theatre with only 4 cm of bowel left in total. This is physiologically devastating and easily qualifies A as 'ultrashort gut syndrome'.

A would be reliant on long term IV access and TPN solution. Long term IV access carries significant risk of infection. Long term TPN carries risk of poor growth, poor development and liver failure. Ultrashort bowel syndrome may necessitate a bowel and possibly liver transplant in the future in order to ensure survival. A's parents loved him deeply, but questioned whether this course of treatment was ethical. Was this life really in their child's best interests? Or was it more appropriate to palliate him.

However, A had a normal heart and lungs. After the initial operation he quickly weaned off the ventilator and was able to breath himself, with no respiratory support. This raised the question that if A was to be palliated, what would the reality of palliation look like.

I would argue that whilst the prognosis from ultrashort gut syndrome is greatly improving, the diagnosis still carries a significant risk of mortality, and in all cases carries a significant burden of harm intrinsic to the treatment itself. Therefore, to my mind it is entirely reasonable for parents to question whether this is in their child's best interests. I think it can be argued that palliation in this situation is appropriate, and that the lack of dependence on a ventilator should not alter the approach to whether or not palliation is appropriate (This was an issue that had caused concern from several clinicians). In addition, I would argue that if we find it ethically acceptable to withhold IV fluids from adults in certain palliative circumstances, that it would also be ethically acceptable to withhold IV nutrition from a neonate with a palliative condition. Feeding via intravenous route is not physiological; it is a medical treatment. If a treatment is not in the patient's best interests, then it is not justified to administer it. Palliative care should instead focus on ensuring that individual is comfortable.

Decisions about quality of life are incredibly divisive and personal. In my opinion where there is a significant burden of treatment, even when there is a potential for increased survival, whether the course of treatment is in the child's best interests must be taken with huge emphasis on the parental perspective, as they know their child and they uniquely are the ones who will be living the outcome alongside their child. For well-informed, realistic parents who are welcoming of the full picture of information and implications of their decision, I believe parents are best placed to make the decision for their child. This position is supported with the legal precedence outlined in *re T. (a minor) (Wardship: Medical Treatment)* 1997. 1 WLR 242.

For A, the treating clinical team strongly felt he should commence TPN. His parents followed the advice of the clinical team.

# European Neonatal Ethics Conference 2019 November 15th

## Oral Abstracts Limits of Viability Presidents Suite 1130-1230

### Abstracts 5-8

Authors: Christine Carlos(1), MD, Bree Andrews, MD/MPH(1) and Naomi Laventhal MD/MA(2)

Institutions: The University of Chicago (1) and The University of Michigan (2)

Contact Information: 5841 S. Maryland, M/C 6060  
Chicago, IL 60637 USA

Phone: 773-702-6210 Fax: 773-702-0764

Email: [bree.andrews@uchospitals.edu](mailto:bree.andrews@uchospitals.edu)

Submission type: Podium or Poster

**Title:** The collective burden of perinatal care in the 22<sup>nd</sup> week of gestation:  
Is the focus of contemporary ethical controversy misplaced?

**Background:** Informed by high-quality, large-scale epidemiologic outcomes studies of extremely preterm infants, ethical controversy surrounding perinatal care of infants born at the margin of gestational viability has increasingly focused on the 22<sup>nd</sup> week of gestation. Hesitation about offering a trial of therapy for infants born 22 and 0/7 to 22 and 6/7 weeks seems at least in part driven by fear of undue burden on the infants themselves, their families, perinatal clinical units and providers, and society.

**Methods:** 24 months of maternal, obstetric and neonatal and discharge records from a single, high- volume high-acuity hospital were reviewed after IRB approval. All cases of infant delivery in the 22<sup>nd</sup> week of gestation were assessed. Decision-making, medical treatments, and NICU outcomes were evaluated.

**Results:** 14 women of 3610 (0.004%) in two years presented either in labor, with rupture of membranes, or significant pre-eclampsia between 20 3/7 and 22 4/7 weeks and were delivered between 22 0/7 and 22 6/7 gestational weeks. Four women were admitted prior to planned elective pregnancy termination for chromosomal or severe fetal anomalies. Of the remaining 10 pregnancies (0.003%), 5 (0.001%) were offered resuscitation based on characteristics at the time of presentation. Amongst those offered resuscitation, 3 women accepted (0.0008%). Two (0.0002%) infants responded to resuscitation and both were discharged to their parents without significant medical technology and without major handicapping conditions at 12 months. One died in the delivery room after unsuccessful resuscitation.

**Discussion/Conclusion:** Although polarizing professional and societal ethical debate continues about resuscitation of infants born at the outermost margin of gestational viability, perinatal care of maternal-infant dyads in the 22<sup>nd</sup> week of gestation represented a tiny fraction of cases in a tertiary medical center, in terms of presentation for care, consideration of a trial of therapy after birth, pursuit of delivery room resuscitation, survival through infancy, and impaired/technology dependent survival. Granular exploration of institutional outcomes has the potential to complement larger-scale epidemiologic outcome studies and alleviate preoccupation with the prospect of undue treatment for mothers/infants presenting at the border of viability.

**Key Message:** Institutional policies allowing consideration of a trial of therapy at 22 weeks' gestation are unlikely to substantially strain the resources of perinatal units or unduly burden society.

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

*Please complete on one page, Arial font size 10. Abstract of no more than 400 words.  
Submission indicates consent for possible publication of this material on the WONEP website and the conference booklet. Please return as a word document by email to [mproveonline@gmail.com](mailto:mproveonline@gmail.com)  
Please read rules for abstract below*

**Submission by:**

Name: Chantelle Tomlinson email: [chantelle.tomlinson1@nhs.net](mailto:chantelle.tomlinson1@nhs.net)  
Institution: Sheffield Children's Hospitals NHS Trust Mobile: 07796 305430  
Specialty & Year: Post-CCT Fellow (Neonates) Wessex Trainee: No  
Contact Address: The Coach House, 3 Broomgrove Mews, Sheffield, S10 2LT

**Submission for:** Both (delete as appropriate)

**Title:** All the small things: An exploration of hands-on care at threshold viability in Japan

**Author(s):** Chantelle Tomlinson

**Abstract:**

**Background & Context:** Supported by a UK Churchill Fellowship, I travelled to neonatal ICUs in Japan & Canada to explore quality improvement, hands on care and the "human aspects" of neonatal care at threshold viability. The Japanese Motherhood Protection Act defined the limit of viability as 22 weeks in 1991. I visited centres with varying approaches to infants born at 22 weeks. I was generously supported to explore current data of the Neonatal Research Network of Japan. Clinical teams with many years' experience of "micro preterms" and their families shared their thoughts, beliefs & practices with me.

**Observations & Findings:** Meaningful outcomes for babies at 22-24 weeks in Japan have consistently been recognised as world leading with respect to survival & other composite outcome measures. Attitude to outcome is such that almost 1/3 of 22 week infants are born by caesarean section, around 1/2 at 23 weeks & 3/4 of 24-25 week infants. Early care often comprises extremely minimal handling for the first 72 hours to mitigate risk of significant IVH; the gentle, patient approach taken is as if they were made of glass. Interesting questions arise in the quest for family involvement and bonding with their baby.

Variation continues across Japan as to the "absolute" cut off for active resuscitation & intensive care to be offered. Some centres implement 22+0 as their lower limit; others adjust this based on a case-to-case basis, whereas many centres consider 22+5 their threshold for active resuscitation. Japanese law prohibits "withdrawal of intensive care" posing intense ethical challenges and moral distress around some critically ill babies or those facing painfully complex challenges. In a number of centres Neonatologists conduct follow-up of these children to 8 or 9 years posing thought provoking additional layers of experience & insight for those clinicians. There has been a steep increase in long-term, home based technology supporting some survivors & expectations of what is possible as well as within the spectrum of "normal" is changing in parallel. Social stigmatisation for families affected by significant sequelae of threshold viability is a pervasive factor & staff reported some families containing themselves to their homes to avoid adverse public judgement.

**Key Lessons:** The extensive Japanese experience caring for 22-24 week infants & achieving impressive long term outcomes, raises opportunities to reflect upon, learn from & translate key lessons in ethical & humane care for our extremely preterm population & their families.

399 words

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**European Neonatal Ethics Conference**  
**Oral or Poster: Abstract Submission**

**Submission by:**

Name: Maria den Boer  
Institution: Leiden University Medical Center  
Speciality & Year: PhD student neonatology/medical ethics, 3<sup>rd</sup> year  
Contact Address: Division of Neonatology, Leiden University Medical Center,  
PO box 9600  
2300RC Leiden, the Netherlands  
Email: [m.c.den\\_boer@lumc.nl](mailto:m.c.den_boer@lumc.nl)  
Mobile: +31645976570  
Wessex Trainee: No

**Submission for:** both

**Title:** Reviewing recordings of neonatal resuscitation with parents: the missing piece of the puzzle

**Author(s):** M.C. den Boer; M. Houtlosser; R.G. van der Stap; R.N.G.B. Tan; M.C. de Vries; E. Lopriore; A.B. te Pas

**Abstract:**

*Background* Recording neonatal resuscitation, including video and respiratory parameters, was implemented for quality purposes at the neonatal intensive care unit of the Leiden University Medical Center. As various studies showed that parental presence during the resuscitation of their child can be beneficial, we offer parents to review recordings of the neonatal resuscitation of their newborn together with a neonatal care provider.

*Objective* To gain insight in parental experiences with reviewing recordings of the neonatal resuscitation of their newborn.

*Methods* Retrospective qualitative interview study combined with participant observations during parental review of recordings.

*Results* Parental review of recordings of neonatal resuscitation was observed in 19 occasions, reviewing recordings of 26 children (13 singletons, five twins, one triplet), of whom five deceased. Median gestational age at birth was 27 5/7 (range 24 2/7 – 38 1/7) weeks. Reviewing recordings occurred median (IQR) 55 (26-80) days after birth. 21 parents (two bereaved; 11 mothers, 10 fathers) were interviewed.

Of all parents approached during this study, only one father did not wish to review the recordings. The main reason to review the recordings was interest in the first minutes of life of their newborn. All parents, including bereaved parents, reported positive experiences with reviewing the recordings, but acknowledged this was also due to timing of the review. Parents of surviving newborns considered their newborn being relatively stable as the most important precondition for a positive experience. Parents of three deceased newborns requested to review the recordings of their newborns during a follow-up appointment, as they felt this would support them during their grieving process. Most interviewed mothers, especially those who underwent a cesarean section, considered the moments directly after the birth of their newborn as 'the missing piece of the puzzle'. They reported that reviewing the recordings helped them to fill this gap and to create a common memory with their partner that was present during neonatal resuscitation, allowing them to cope together. Some fathers reported to consider reviewing the recordings as a valuable possibility to share their experiences with their partner.

Parents often stated to be proud of their newborn's breathing effort as visualized by the respiratory parameters. Many mothers were touched by watching the first contact between father and child. Reviewing recordings frequently resulted in parental appreciation for the providers' efforts to deliver the best care to newborns and to be transparent to parents.

*Conclusions* Parents consider reviewing recordings of neonatal resuscitation beneficial.

# European Neonatal Ethics Conference

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Please read rules for abstract below*

**Submission by:**

Name: Zahreddin Abusalah email: [zahreddin.abusalah@mediclinic.ae](mailto:zahreddin.abusalah@mediclinic.ae)  
Institution: Neonatal Intensive Care Unit, Mediclinic City Hospital, Dubai, UAE Mobile: +971567867945  
Specialty: Consultant Neonatologist Wessex Trainee: No  
Contact Address: PO Box 300281 Dubai, United Arab Emirates

**Submission for:** Podium

**Title:** Counselling of Parents Of Premature Babies. A novel approach

**Author(s):** Zahreddin Abusalah

**Abstract:****Introduction:**

Counselling of parents expecting a preterm baby is a challenging experience that requires special expertise and knowledge. Despite its importance, there is no standard approved approach to conduct it.

**Aims:**

- To highlight the importance of effective communication with parents.
- To suggest a structured approach for counselling.

**Methods:**

The presentation will provide an overview of principles and contents of the counselling session. Although this has been the subject of several reviews and statements, there is a lack of a structured approach for conducting the consultation.

Colleagues in Oncology have suggested several protocols to discuss the clinical condition with their patients. Some of these protocols appear to be suitable to be adopted for use in counselling parents.

This paper will discuss the adoption of the SPIKES protocol that was originally described to disclose unfavourable clinical information to patients with cancer.

Outcomes of premature infants contribute to a major part of the consultation with parents. Therefore, the presentation will examine the latest available evidence about various aspects of outcomes of preterm babies.

The presentation will include video clips from my teaching video on counselling. The video was recorded with real parents of a premature baby.

**Conclusion:**

A structured standard approach will help the healthcare professional to perform such a stressful task efficiently in a reproducible model. This may serve as a training tool too. To my knowledge, the counselling video of this presentation is the first of its kind in utilising a structured approach with the participation of real parents.

**Total Word Count (Abstract Body Only): 248 (References are available but not included to keep to the limit of the word count)**

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# European Neonatal Ethics Conference

## Oral Presentation Palliative Care

*Mike Channon Suite November 15th 1130-1230*  
*Instructions 12 minutes presentation time with 3 minutes for questions*  
*Award Category-Best Oral Presentation*

**Submission by:**

Name: Min Sun Kim

email: mskim81@snu.ac.kr

Institution: Seoul National University Hospital

Mobile: +82-10-2724-5345

Specialty & Year: Pediatric Palliative Care

Wessex Trainee: No

Contact Address: 101, Daehak-ro, Jongno-gu, Seoul, Republic of Korea

**Submission for:** Poster

**Title:** Conflict associated with decisions on life-sustaining treatment in a neonatal intensive care unit at a tertiary hospital in South Korea

**Author(s):** Min Sun Kim, In Gyu Song, Ee-Kyung Kim

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

**Background**

In South Korea, to enhance a patient's involvement in making decisions, and respect their end-of-life wishes, the *Act on Decisions on Life-Sustaining Treatment for Patients at the End-of-Life* was enforced in 2018. The act permits a doctor to determine to withdraw or withhold life-sustaining treatment for patients with a state of imminent death. If the relevant patient is a minor, the doctor in charge shall explain such matters to the patient and his/her legal representative.

**Method**

We reviewed ethical conflict cases associated with decisions on life-sustaining treatment in a neonatal intensive care unit (NICU) at a tertiary hospital in South Korea. The hospital is a national university hospital which has 1,778 beds (including 315 paediatric beds which 40 are NICU beds). There were 1,201 admitted patient deaths in the hospital, and among these, 16 cases occurred in the NICU. The hospital ran an ethical committee, but it usually resolved disputes over legal issues. With enforcement of the law in 2018, the committee redefined their role and started clinical, ethical support (consult, advise, review). In 2018, 31 cases were consulted by the committee, and four cases of those were requested from the NICU.

**Results**

Three cases involved preterm infants who were born before 30 weeks of gestation with complications (severe pulmonary hypertension, total anomalous pulmonary venous return [TAPVR], and severe intraventricular haemorrhage), while one baby was a full-term infant who had severe brain injury associated with birth asphyxia. The committee was consulted for their opinion on withholding life-sustaining treatment or operation (ligation of patent ductus arteriosus for TAPVR, ventriculoperitoneal shunt for hydrocephalus). All parents wished to withhold treatment or refuse surgery because of the babies' poor neurologic prognosis, but doctors hesitated—because of legal and ethical issues—over making decisions. The committee made decisions according to the law and principles of medical ethics and advised parents and healthcare providers. Two patients died following the consultation, and two were discharged from the hospital.

**Conclusions**

Despite the law being enforced, healthcare providers still face difficulties in making decisions in South Korea. Decisions on neonates need deliberation over patients' and their families' best interests which could be affected by long-term outcomes and social support. Compared to the reports from Western countries, NICU parents in South Korea tend to want to withhold or withdraw life-sustaining treatment for babies with poor neurologic prognosis. Cultural differences and a lack of social support at home may affect this difference.

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Please read rules for abstract below*

**Submission by:**

Name: Peta Coulson-Smith

Institution: Clinical Ethics and Law (CELS) University of Southampton

Mobile: 02381 205082

email: [P.K.Coulson-Smith@soton.ac.uk](mailto:P.K.Coulson-Smith@soton.ac.uk)

Specialty & Year: Paediatrics ST5, Clinical Research Fellow Ethics and Law

Wessex Trainee: Yes on OOPR

Contact Address: Clinical Ethics and Law, Mailpoint 127, Rm 2013, Centre for Cancer Immunology  
University of Southampton, Southampton General Hospital, Tremona Road, Southampton. SO16 6YD

**Submission for:** Poster or oral presentation

**Title:** Charlie's Law: Should the Justification for Withdrawal of Life-Sustaining Treatment for Children on the Intensive Care Unit be changed from Best Interests to Significant Harm?

**Author(s):** Dr Peta Coulson-Smith

**Abstract:**

Several high-profiled legal cases regarding withdrawal of life-sustaining treatment (LST) have been extensively reported in the media in recent years. Justification of such decisions have been disputed by parents, the public and in the courts, with previously assigned methods of decision-making around withdrawal of LST questioned. Following the tragic case of Charlie Gard, there has been a great deal of attention drawn to the 'best interests' standard and *Charlie's Law* has been drafted with a view to changing the threshold at which doctors can justify the withdrawal of LST and parental decisions might be overridden. The threshold proposed in Charlie's Law is that of 'significant harm'.

At first glance, moving from a best interests assessment to a significant harm threshold appears to *increase* the threshold for withdrawal of LST or overriding parental autonomy, and this is likely to be the motivation for such a change in the law. Significant harm, is however, more poorly defined than the best interests standards and, although this standard appears to work as a protective mechanism in a social context for removing children into care, it is untested as a singular mode of action in a healthcare context. Moreover, it is apparent that a significant harm threshold context is already used as part of a best interests standard in the context of exploring the withdrawal of LST. The Royal College of Paediatrics and Child Health (RCPCH) Guideline acknowledges that harm, coupled with futility, serves as rationale for withdrawal of LST. Clarifying the best interests assessment and its parameters to ensure a more cohesive judicial and clinical application, developing clinical ethical reasoning skills alongside improved communication and transparency with parents would provide a better way forward for children who may need LST withdrawn, than the change that Charlie's Law proposes.

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**Submission by:**

Name: Lars Garten, MD

email: [lars.garten@charite.de](mailto:lars.garten@charite.de)

Institution: Charité Universitätsmedizin Berlin

Mobile: 0049 – (0)30-450-566122

Wessex Trainee: No

Specialty & Year: Pediatrics (since 2007), Neonatology (since 2011), Palliative Care (since 2014)

Contact Address: Lars Garten / Klinik für Neonatologie / Charité Universitätsmedizin Berlin / Augustenburger Platz 1 / D-13353 Berlin / Germany

**Submission for:** Poster

**Title:** End-of-Life Decisions 20 Years after EURONIC: Neonatologists' Self-Reported Practices, Attitudes, and Treatment Choices in Germany, Switzerland, and Austria

**Author(s):** Katja Schneider, MD<sup>1</sup>, Boris Metze, BSc<sup>2</sup>, Christoph Bühner, MD, PhD<sup>2</sup>, Marina Cuttini, MD, PhD<sup>3</sup>, and Lars Garten, MD<sup>2</sup>

<sup>1</sup>Department of Neonatology, GFO Kliniken Bonn, Bonn, Germany

<sup>2</sup>Department of Neonatology, Charité-Universitätsmedizin Berlin, Berlin, Germany

<sup>3</sup>Clinical Care and Management Innovation Research Area, Ospedale Pediatrico Bambino Gesù, Rome, Italy

**Abstract:**

**Background:** The European Project on Parents' Information and Ethical Decision Making in Neonatal Intensive Care Units (EURONIC) survey carried out in 1996-1997 explored the transmission of information to parents and the ethical decision making process in neonatal intensive care from the perspective of health personnel and in relation to the legal, cultural, social, and ethical backgrounds of various European countries. Since the time of the EURONIC data collection, several countries (among them Germany, Austria, and Switzerland) have implemented guidelines and introduced changes in the legislation related to the ethical dilemmas addressed by the EURONIC project.

**Objective:** To assess changes in attitudes of neonatologists regarding the care of extremely preterm infants and parental involvement over the last 20 years.

**Methods:** Internet-based survey (2016) involving 170 tertiary neonatal intensive care units in Austria, Switzerland, and Germany using the European Project on Parents' Information and Ethical Decision Making in Neonatal Intensive Care Units questionnaire (German edition) with minor modifications to the original survey from 1996 to 1997.

**Results:** The 2016 survey included 104 respondents (52.5% response rate). In 2016, significantly more neonatologists reported having ever withheld intensive care treatment (99% vs 69%) and withdrawn mechanical ventilation (96% vs 61%) or life-saving drugs (99% vs 79%), compared with neonatologists surveyed in 1996-1997. Fewer considered limiting intensive care as a slippery slope possibly leading to abuse (18% vs 48%). In the situation of a deteriorating clinical condition despite all treatment, significantly more neonatologists would ask parental opinion about continuation of intensive care (49% vs 18%). In 2016, 21% of German neonatologists would resuscitate a hypothetical infant at the limits of viability, even against parental wishes.

**Conclusions:** Withholding or withdrawing intensive care for extremely preterm infants at the limits of viability with parental involvement has become more acceptable than it was 20 years ago. However, resuscitating extremely preterm infants against parental wishes remains an option for up to one-fifth of the responding neonatologists in this survey.

**Ref.:** Schneider et al. End-of-Life Decisions 20 Years after EURONIC: Neonatologists' Self-Reported Practices, Attitudes, and Treatment Choices in Germany, Switzerland, and Austria. J Pediatr 2019;207:154-60.

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**Submission by:**

Name: **Beatrice Lechner MD**

email: [blechner@wihri.org](mailto:blechner@wihri.org)

Institution: Women & Infants Hospital of Rhode Island/Brown University

Mobile: +1 203 400 5655

Specialty & Year: Neonatology

Wessex Trainee: Yes / No

Contact Address: 101 Dudley St. Providence, RI 02905, USA

**Submission for:** Both (delete as appropriate)

**Title: "Quality of Life": Parental and neonatologist perspectives**

**Author(s): Shannon Adams, Richard Tucker, Beatrice E. Lechner**

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

**Background**

*In the NICU, deaths can be broadly divided into two primary categories: (a) "negotiated" - those infants with stable physiology who die due to the discontinuation of clinical intervention, and (b) "unavoidable" - those with unstable physiology who die despite intensive care or intervention due to unmanageable causes. The former often takes prognosis into consideration, as well as what the medical profession calls potential "quality of life" (QOL). The concept of QOL is frequently used in clinical discourse, however, despite the implications of the decisions made based on this enigmatic, somewhat controversial metric, it has no conclusive definition. The aim of this study is to evaluate how the families of NICU patients define quality of life for their infant as compared to neonatologists.*

**Design/Methods**

*Surveys were developed and administered to eligible families via the social media networks of participating support groups. Analysis was conducted using REDCap and standard statistical methods. Focus group recruitment utilized local advocacy groups' listservs. Audio recordings were obtained and analyzed with NVivo software.*

**Results**

*The survey received 901 responses. The mean rank for the importance of QOL on a scale of 1-10 in determining whether to continue life sustaining therapies was 8.2. For prognostic indicators associated with a "bad" QOL, need for a ventilator, inability to get out of bed, tracheostomy, nonverbal status, and adult incontinence ranked the highest. Parents were more likely to accept higher levels of disability, while neonatologists were more likely to accept higher levels of dependence on medical equipment. Qualitative analysis of both the focus group transcripts and survey responses, showed that pain, brain damage, familial support, and human connection were mentioned with the greatest frequency by participants when considering QOL for NICU patients.*

**Conclusions**

*Parents of NICU infants as well as neonatologists believe that QOL is an important metric to consider when determining whether to continue life sustaining therapies for infants in the NICU. These data indicate that parents are primarily concerned with their child's pain, brain function, and ability to communicate, and that parents and neonatologists differ in their assessment of quality of life.*

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Please read rules for abstract below*

**Submission by:**

Name: **Prof Maria Brenner**

email: [brennerm@tcd.ie](mailto:brennerm@tcd.ie)

Institution: **Trinity College Dublin**

Mobile:

Specialty & Year:

Wessex Trainee: Yes / No **NO**

Contact Address: **School of Nursing & Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2, D02 T283, Ireland,**

**Submission for: / Poster /** (delete as appropriate)

**Title: Evolving influences on the initiation of life-sustaining technology in children**

**Author(s): Dr Denise Alexander, Jessica Eustace-Cook, Prof Maria Brenner**

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

**Background:** The emergence of sophisticated life-sustaining medical technology in paediatrics has saved thousands of lives, however, little is understood about the dynamic circumstances within which the initiation of technology dependence takes place. The central purpose of the ERC-Funded TechChild project is to investigate the influences (conscious and unconscious) surrounding the initiation of technology dependence when a child is critically ill. This aim of review was to identify how decisions were made in the past, and what current issues require further exploration and consideration.

**Methods:** Using broad search terms to describe key concepts, such as technology dependence, physical disability, chronic illness and complex care needs of children, we identified 1133 scientific papers ranging from the 1970s to the present day. A three-stage process of title and abstract screening, initial full-text scanning, and in-depth full text reading resulted in 178 relevant papers. Although relatively few papers specifically focused on the initiation of technology dependence in children, relevant discussions were identified around decision-making in intensive care, and the withdrawing or withholding treatment at the end of life.

**Results:** We identified three inter-related broad themes: the ability of life-sustaining technology to alter the meaning of futile care; dissonance in perspectives of decision-making; and the emergence of joint-decision making. Changes within these themes describe the evolution of the complex and challenging ethical debates about the initiation or non-initiation of life sustaining technology. Changes in approaches to the use of life-sustaining technology by physicians; society's attitudes to technology; and the increasing influence of wider perspectives on decisions, such as child well-being, were described by the literature. The fundamental philosophies of 'preserving life at all costs' or 'do no harm' have been challenged as insufficient to guide ethical practice; the role of physicians as lone, impartial decision makers, and the role of parents from passive observers has changed as the need for collaborative decision processes becomes apparent to navigate the complex and new ethical environment.

**Conclusions:** Decisions about the initiation or not of life-sustaining technology has created ethical challenges that have changed the traditional role of medicine, of physicians and of parents. Attempts to find decision-making consensus in the context of challenging ethical debates and very different viewpoints are difficult.

**Key messages:** There remains a lack of evidence about the current overt and implicit influences on decision-makers surrounding the initiation of technology dependence. Understanding these will lead to greater clarity in decision-making in this context.

## ABSTRACTS FOR EUROPEAN NEONATAL ETHICS CONFERENCE

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# European Neonatal Ethics Conference

## Oral Abstracts Potpourri

*Please note your session will be on the 15th of November in the Mike Channon Suite from 1400 to 1520. Presentations are 12 minutes with 3 minutes for questions please*  
*Prize Category Best Oral Abstract*

**Submission by:**

Name: Chatziioannidis Ilias  
Institution: Papageorgiou Hospital, NICU  
Specialty & Year: Consultant in Neonatology, 2004  
Contact Address: Ring Road N. Efkarpia, Code Number 56403

email: drilias@windowsslive.com  
Mobile: +30 6977244542  
Wessex Trainee: Yes / No

**Submission for:** Podium / Both (delete as appropriate)

**Title:** END-OF-LIFE DECISION MAKING ETHICAL ISSUES IN NICUs: ATTITUDES and SELF REPORTED PRACTICES

**Author(s):** Chatziioannidis I, Giougi E, Iliodromiti Z, Boutsikou T, Iacovidou N

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

**Background:** End-of-life decision making ethical issues (ELDMei) in neonatology are controversial. Additionally, data in the literature on attitudes and personal values of NICU personnel confronted with these issues are scarce.

**Objectives:** To explore the variability of attitudes and values among NICU personnel and to record self-reported practice of ELDMei. To the best of our knowledge this is the first time a similar study was conducted in Greece.

**Design:** A self-administered survey was conducted during 2018-2019 in 7 NICUs of northern Greece.

**Participants:** 122 healthcare physicians and nurses were the study subjects.

**Main Outcome Measures:** The questionnaire included information on demographic data; an attitude and personal beliefs scale score, measuring views regarding sanctity of life (score 1) vs. quality of life (value 5); self-report participation on intensive care interventions/practices in newborns with poor (neurologic) prognosis, or at terminal stage, or at the limit of viability; intensive care interventions/ practices for ELDMei.

**Results:** The response rate was 61 % (18.2%-88.2%). Working in a public sector NICU ( $p=0.01$ ), higher educational level ( $p=0.065$ ), having more job time experience in neonatology ( $p=0.001$ ), research participation ( $p=0.038$ ), being physician ( $p=0.030$ ), and working fewer hours/week ( $p=0.009$ ) were factors associated with a pro-quality of life view. Interestingly NICU personnel rating religion as non- important exhibited a tendency towards higher scores, albeit non significant. Physicians' self-reported participation on intensive care interventions in newborn cases with poor (neurologic) prognosis (88.2% (81.1%)), or at terminal stage (87.9%), or at the limit of viability (87.9%) was much higher than that of nurses ( $p<0.001$ ). The more common intensive care interventions /practices for ELDei were a) to continue treatment without adding further support (48.3%), b) to administer drugs (analgesics/sedatives) even at the risk of respiratory suppression or even death (23.7%), c) withholding emergency intervention (13.6%), while the least common was withdrawing mechanical ventilation (0.9%).

**Conclusions:** Several specific factors were found to be associated with a higher attitude score and a pro-quality of life pattern, although importance of religion was not significantly associated. A vast majority of neonatologists were involved in ELDMei with a substantial variation of practices, most commonly being continuation of care without adding further support, drug administration and withholding emergency intervention.

**Key messages:** This is the first study in Greece investigating attitudes of NICUs' personnel on the value of life and their association to personal or professional background. As personal attitudes govern practices in ELDMei certain interventions/practices of decision making are presented.

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Please read rules for abstract below*

**Submission by:**

Name: Emma Nottingham

email: [Emma.Nottingham@winchester.ac.uk](mailto:Emma.Nottingham@winchester.ac.uk)

Institution: University of Winchester

Mobile: 07449596284

Specialty & Year: Senior Lecturer in Law

Wessex Trainee: No

Contact Address: University of Winchester, Sparkford Road, Winchester, SO22 4NR

**Submission for:** Podium

**Title:** Best interests of the child in the age of Social Media

**Author(s):** Emma Nottingham

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

In the recent cases of Charlie Gard and Alfie Evans, social media was used as a campaign tool to garner support for young children with life limiting conditions. During their short lives, Charlie Gard and Alfie Evans were tagged on social media platforms including Facebook and Twitter. The purpose of this initially appeared to be to raise funds, so that the children could receive alternative treatment abroad. However, when the court informed the parents that they were not permitted to remove their children from where they were being treated, the fundraising campaign escalated into a campaign to overturn the decisions of the doctors and the courts and prevent life-sustaining medical treatment being withdrawn.

The cases of Charlie Gard and Alfie Evans raise significant ethical and legal concerns about the impact of social media campaigns on the privacy of young children with life-limiting conditions, as well as their families and those involved in their medical treatment. This paper explores possible issues that can arise when the parents of a child with a life-limiting condition embark on a social media campaign. It considers: whether the care and treatment of other children could be affected; the impact on the moral distress of medical professionals; the confidence of parents in the ability of medical professionals treating children to act in their best interests; the public perception of the medical profession and the NHS. In response to these issues, this paper suggests ways in which the children of the social media age, and those who care for them, can be better protected.

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conference booklet. Please return as a word document by email to [mproveonline@gmail.com](mailto:mproveonline@gmail.com)  
Please read rules for abstract below*

**Submission by:** Name: Rebecca Greenberg RN, PhD email: [rebecca.greenberg@sinaihealthsystem.ca](mailto:rebecca.greenberg@sinaihealthsystem.ca)

Institution: Mount Sinai Hospital & Department of Paediatrics, Faculty of Medicine, University of Toronto

Mobile: 1-647-866-6089

Specialty & Year: Bioethics (Doctorate of Philosophy (Bioethics) 2008)

Wessex Trainee: No

Contact Address: Bioethics Department, Mount Sinai Hospital, 600 University Ave, Toronto, ON M5G 1X5, Canada

**Submission for:** Podium / Poster / Both (delete as appropriate)

**Title:** Supporting Parental Decision-Making in the Neonatal ICU: The Experience of Moral Distress and 'Moral Schism'

**Author(s):** Rebecca Greenberg, Jonathan Hellmann, Gabriella Foe

### **Abstract:**

Ethical dilemmas in the critical care context have caused healthcare practitioners to experience moral distress. Given that decision making in the neonatal ICU (NICU) is often value-laden with significant ramifications, parents may experience both value conflicts internally and/or with the healthcare team. The rise of technology, and the value-laden conflicts associated, only increases the likelihood of ethical dilemmas arising. We propose that moral distress is also experienced by parents faced with making value-laden decisions for their child in the NICU. We hypothesize that parents will more commonly experience what we have termed "moral schism" in these scenarios. "Moral schism": parents encountering significant internal struggle with their personal values when making decisions, which results in doubt and distress as to the right course of action, and is not usually caused by misunderstandings, misperceptions, or misinterpretation of the situation. This phenomenon is contrasted with moral distress where there is limited internal struggle, no doubt as to the right course of action, but parents are precluded from executing, what they believe to be, the right action. We focus on parental experience of decision making in the NICU. We will explore factors that appear to contribute to both moral distress and "moral schism." We suggest that "moral schism" is an underappreciated, and often hidden, concept that needs to be explicated. We also suggest actions that healthcare providers can take in effort to minimize parental moral schism and moral distress.

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# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

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### Submission by:

Name: Dr Trisha Prentice

email: trisha.prentice@rch.org.au

Institution: Royal Children's Hospital, Melbourne

Mobile: +61 407879229

Specialty & Year: Neonatology

Wessex Trainee: No

Contact Address: 50 Flemington Rd, Parkville, VIC, AUS 3015

**Submission for:** Podium / Both

**Title:** Moral distress arising from decision-making conflicts: how much should we accept?

### Abstract:

**Author(s):** Trisha M Prentice<sup>1,2,3,4</sup>, Lynn Gillam<sup>4,5</sup>, Peter G Davis<sup>2,6</sup>, Annie Janvier<sup>7</sup>

<sup>1</sup> Neonatal Medicine, Royal Children's Hospital, Melbourne, Victoria, Australia

<sup>2</sup> Newborn Research, Royal Women's Hospital, Melbourne, Victoria, Australia

<sup>3</sup> Murdoch Children's Research Institute, Melbourne, Victoria, Australia

<sup>4</sup> Melbourne School of Population and Global Health, University of Melbourne, Melbourne, Victoria, Australia

<sup>5</sup> Children's Bioethics Centre, Royal Children's Hospital, Melbourne, Victoria, Australia

<sup>6</sup> Department of Obstetrics and Gynaecology, University of Melbourne, Melbourne, Victoria, Australia

<sup>7</sup> Department of Pediatrics, Division of Neonatology, Clinical Ethics Unit, Palliative Care Unit, Unité de Recherche en Éthique Clinique et Partenariat Famille, CHU Ste-Justine, Montreal, Quebec, Canada

### Abstract:

#### Background:

Moral distress arises when clinicians feel constrained from acting in what they perceive to be a patient's best interests. In the intensive care setting it is not uncommon for individuals with different values to disagree on a course of treatment; advancing technology brings with it both hope of cure and moral uncertainty. In the era of shared-decision making, clinicians across all disciplines can feel constrained to provide care (perceived to be inappropriate) in line with family wishes. We aimed to provide a longitudinal account of moral distress in relation to healthcare providers' judgements of appropriate level of care, perceived parental wishes and changing illness severity in the preterm population.

**Methods:** We followed 100 neonates born <28 weeks from birth until discharge from tertiary level care. Four clinicians of different types caring for each baby completed at regular intervals a survey that included predictions of death and disability and preferred level of care provision. Wocial's Moral Distress Thermometer (MDT) was used to measure moral distress intensity in addition to qualitative explanations for distress experienced. Neonatal parameters were collected simultaneously, and their relative illness severity recorded.

**Results:** Mean gestation was 25+6 weeks, mean weight 823g. Moral distress occurred on 687/4587 (15%) of survey occasions. Discordances between clinician preferences and parental wishes were rare, occurring in 254/4587= 6% of survey occasions, yet were strongly associated with moral distress ( $p<0.001$ ). However, the belief parents 'wanted too much' aggressive intensive care accounted for 24% of moral distress occasions. Nurses and trainees experienced moral distress of higher intensity than neonatologists in such circumstances despite making similar predictions of death and disability. Neonatologists had less discordance with parental wishes regarding the preferred level of care than other clinicians, even when they personally believed survival was not in the patient's best interests.

**Conclusions:** The perception that parents unreasonably 'want too much' aggressive intensive care for their child remains a strong determinant of moral distress. Yet the intensity of distress experienced differed between professional cohorts despite similar predictions of death/disability and judgements on the most appropriate level of care provision.

In this presentation we will discuss some of the dynamics of moral distress when conflicts arise within the NICU. We will consider what responses the presence of moral distress should (and shouldn't elicit) and consider reasons for variations of experience across provider groups.

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

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### **Submission by:**

Name: Miss Avantika Arun

Institution: St. Michael's School

email: avantikaarun2001@gmail.com

Mobile: 07585 320 378

Specialty & Year: Year 13 student

Contact Address: 41 Westport Avenue, Mayals, Swansea, SA3 5EQ

Wessex Trainee: No

**Submission for:** Both oral and poster presentation

**Title:** The Artificial Womb: Exploring the Ethical Minefield of Extreme Prematurity

**Author(s):** Miss Avantika Arun, Dr. Arun Ramachandran

### **Abstract:**

#### **Background:**

The management of extremely premature babies at the borders of viability remains a clinical and ethical challenge. Current technologies supporting neonatal intensive care for babies born < 26 weeks have reached their limit for pushing back the limits of viability whilst maintaining neuroprotection. Emerging technology using artificial womb (AW) in lamb models have demonstrated good outcomes for an equivalent gestational age. AW is a sealed extracorporeal device that enables us to prolong the gestational period by mimicking the natural environment of the uterus. Human trials for the most advanced AW, (Biobag project), are expected in 2 years.

This survey was undertaken as part of an A-level Extended Project Qualification, to gauge public opinion regarding adaptation of AW in clinical practice.

#### **Methodology:**

A questionnaire survey using google forms was conducted in February 2019 following a literature review on this topic. The survey assessed respondents' general attitudes and ethical concerns towards the artificial womb concept. A survey link was circulated via social media (Snapchat, WhatsApp, email) allowing informed voluntary participation.

#### **Results:**

125 responses were received from a relatively heterogeneous set of participants; consisting of students, laymen, academics and healthcare professionals ranging from 15 – 75 years. There was an overrepresentation of females at 64%.

Majority agreed with the use of the AW to save their baby if it were in danger. 71% would use it to improve outcomes for IVF, 37.9% to support homosexual couples to have babies, 41.8% to abolish surrogacy and 34.6% to reduce abortions. Among those opposed to AW, the reasons stated included perceived complications and moral trepidations. 74.2% of respondents were against allowing women to use AW to avoid the pains of childbirth and its use to aid career progression.

**Conclusions and key messages:**

Public opinion supports introduction of AW technology to kick-start a new era in neonatal care to improve outcomes for extremely premature babies provided there is high quality research evidence to support its use. Uses of the technology for non-medical purposes, with alteration of the normal human reproductive course, do not have widespread support and are likely to be controversial.

Further research is required to refine the technology, establish safety protocols and define expected outcomes. Legal framework and ethical guidelines will need to be developed to ensure appropriate use, especially in association with gene editing technologies. Family integrated care techniques to ensure bonding between parents and their baby should be developed.

**Submission by:**

Name: Abigail Nye email: abigail.l.s.nye@gmail.com  
Institution: Royal United Hospital, Bath Mobile: 07982210514  
Specialty & Year: ST4 Paediatrics Wessex Trainee: No  
Contact Address: 439 Soundwell Road, Bristol, BS15 1JT

**Submission for:** Both (delete as appropriate)

**Title:** Ethical issues in decision-making regarding surgery for children with Trisomy 18

**Author(s):** Abigail Nye, Heather Sharon Hodgson, Fiona Finlay

**Abstract:**

Trisomy 18 has traditionally been regarded as a lethal condition, and medical intervention has therefore been withheld from affected children due to concerns regarding perceived short life expectancy and severe disability. However, studies have shown that both 1 year and 5 year survival increase with intensive medical intervention; and parental surveys have revealed that parents cope well, value their children and appreciate a quality of life for their children.

Decision-making for children with Trisomy 18 is complex, due partly to the heterogeneous nature of the condition. Currently, although 91% of children with Trisomy 18 have congenital heart disease, only 7% undergo cardiac surgery, however children who had surgery had better survival rates than those who did not. This statistic is difficult to interpret, as children with more severe cardiac lesions, or other life-limiting co-morbidities, are less likely to be offered surgery than those with relatively simple and reparable defects.

Traditionally, decisions regarding interventions were made by the physician using the paternalistic model of healthcare. There is an increasing move to a collaborative physician-parent model, in which the "expert-parent" voice is heard, and decisions are made jointly, weighing up the relative benefits and burdens of treatment for an individual child. Ethical issues to consider include: the best interests of the child (taking into consideration the child's quality of life, and potential pain and suffering with and without the intervention); futility of a proposed treatment; parental autonomy in decision-making; and resource allocation. Moreover, the child must be considered within the context of their family - it is therefore important to consider the impact on parents and siblings.

Quality of life assumptions are inherently subjective, and it is difficult to truly understand how to apply the standards of beneficence and non-maleficence to any child with a disorder in which there is profound disability. The "lethal anomalies" seen commonly in Trisomy 18, such as congenital heart disease, would usually, if not invariably, be treated in an otherwise healthy infant. It has therefore been argued that the decision not to treat these conditions in Trisomy 18 demonstrates an implicit normative view about quality of life.

It is therefore essential that decisions regarding surgery or intensive medical interventions for children with Trisomy 18 are made in collaboration with the parents. Counselling of parents must include: accurate survival data; discussion regarding developmental outcome without preconceptions about quality of life; and respect for the family's values and choices.

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

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**Submission by: Abigail Callender-Iddon**

Name: Abigail Callender-Iddon

email: abigail.callender-iddon@nhs.net

Institution: Airedale General Hospital

Mobile: 07855235873

Specialty & Year:

Wessex Trainee: No

Contact Address: 24 Worcester Avenue, Leyland. PR253JN

**Submission for:** Both

**Title:** Parental Perspectives on End of Life care in Neonates.

**Author(s):** Abigail Callender-Iddon

**Abstract:**

**Background:**

“Palliative care is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond.” Perinatal palliative care is an emerging field in the UK. This study compares parental experiences of their newborn babies’ end of life care and palliative care. There is very little systematic research in the area of perinatal palliative care.

**Aims:**

This study examined the parental experiences of their newborn babies’ end of life and palliative care services provided within the Yorkshire and Humber region in the UK.

**Methods:**

The research was qualitative using in depth face to face audio taped interviews of 7 bereaved parents. An inductive approach to thematic analysis was carried out on the transcripts of the audio taped interviews. 2 tertiary neonatal units and 2 children's hospices in the Yorkshire and Humber region participated in the study.

## Results:

There were 5 overarching themes identified: 'Diagnosis', 'The parent of a dying baby', 'The baby as an individual and part of the family unit', 'There's nothing more that could be done' and 'Bereavement'.

Core theme	Sub themes
Diagnosis	Initial Reactions
	Uncertainty and Hope
The Parent of a Dying Baby	Parental Support
	Memorable Conversations with Staff
	Environment
The Baby as An individual and Part of the Family Unit	Making Memories
	Parental involvement and choice
	Wider Family and Friends
	Defying Expectations
	Valuable Time spent with Baby
There's Nothing More that Could Be Done	Shift in Parental perspective
	Recognizing Death
Bereavement	Aftermath
	Validation of Parental Experience and baby's Life
	Unwanted Mail

## Conclusion:

Looking after the parent and the family unit is just as important as meeting the end of life care needs of the baby.

Parents reported that good end of life care was provided in both the hospital and hospice setting, however the hospice environment afforded parents more privacy, space and options in terms of facilities.





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Please read rules for abstract below*

**Submission by:**

Name: Alice Bryant

email: [alice.bryant@nhs.net](mailto:alice.bryant@nhs.net)

Institution: Aberdeen Maternity Hospital

Mobile: 07943674945

Specialty & Year: Paediatrics ST2

Contact Address: 52 Beechwood Avenue, Aberdeen, AB16 5BP

**Submission for:** Poster

**Title:** Should nasogastric feeding be used to support breast feeding in babies who are developmentally capable of taking expressed milk from a bottle?

**Author(s):** Alice Bryant

**Abstract:**

*An ex-preterm baby who had received only expressed breast milk was near term and establishing breast feeds. The baby's mother was unwilling to give her baby bottles of expressed milk and established exclusive breast feeding by staying in the neonatal unit. Prior to discharge the mother had an outside commitment and needed to leave the neonatal unit for several hours. She requested that the nasogastric tube be repassed to give expressed breast milk while she was unavailable for breastfeeding.*

*Nasogastric and orogastric feeding are commonly used to support the establishment of breast feeding and bottle feeding in premature and sick babies with the expectation that there will be a gradual transition to the feeding method chosen by parents when the baby is developmentally capable. Many babies will gain the ability to bottle feed prior to the establishment of full breast feeding and this can allow early establishment of suck feeds facilitating earlier discharge to home and transitional care. Some parents who are seeking to exclusively breast feed will reject the use of bottles to administer expressed breast milk.*

*Ethical issues would include the conflicts between the rights of the child and parent. The child needs to receive the most developmentally optimal feeding experience and be cared for by their family in the family environment as soon as medically possible. They also need to avoid the discomfort of a medically-unnecessary feeding tube. The wider community needs to avoid the unnecessary expense of caring for discharge-capable babies in a neonatal unit. In contrast the parents need to retain control over a fundamental choice made by all parents at a time when so many choices about their baby's health and care are made by others. Their right to respect and to make decisions for their family is fundamental when considering parental rights and choices. Parents who choose to exclusively breast feed rather than breast feed and give expressed breast milk from a bottle may also be responding to information given to pregnant women and new mothers about avoiding bottles and they may fear that their baby will not breast feed if given a bottle and they will subsequently not manage to establish breast feeding. Challenging feeding decisions and possibly undermining standard breastfeeding information could cause conflict between the family and staff and undermine the confidence of parents when they are anticipating discharge.*

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**Submission by:**

Name: Alice Cavolo

Institution: KULeuven

Specialty & Year: PhD, year 1

Contact: Address: Centre for Biomedical Ethics and Law  
Kapucijnenvoer 35 Box 7001  
3000 Leuven

email: [alice.cavolo@kuleuven.be](mailto:alice.cavolo@kuleuven.be)

Mobile: 0032 0497 286241

Wessex Trainee: No

**Submission for:** Podium

**Title:** Physicians' attitudes toward resuscitation of Extremely Premature Infants

**Author(s):** Alice Cavolo, Bernadette Dierckx de Casterlé, Gunnar Naulaers, Chris Gastmans

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

Deciding whether to resuscitate extremely premature infants (EPIs) is clinically and ethically difficult. Mortality and morbidity of EPIs vary greatly depending on a large number of factors (e.g. gestational age, provision of prenatal steroids, gender, birthweight, occurrence of postnatal events) making the individual prognosis difficult to assess. This clinical uncertainty in turn generates moral uncertainty. In fact, it makes it difficult to distinguish when resuscitation is appropriate and when physicians "are going too far". Clinical and ethical uncertainties are reflected in the variety of practices across countries and institutions. This suggests that deciding whether to resuscitate EPIs depends, at least partly, on the attitudes of the individual physicians making the decision. Therefore, the aim of our systematic review is to understand physicians' attitudes toward resuscitation of EPIs and the factors influencing such attitudes. We conducted a systematic search of Pubmed, Web of Science, Scopus, and Embase. Only English articles reporting on empirical studies of physicians' attitudes toward resuscitation of EPIs were included. The articles were repeatedly read to identify themes. Then, data were tabulated, compared, and analyzed descriptively. Thirty-four articles (33 quantitative studies and one qualitative) originating from 27 countries across the world were found eligible.

Our results show that physicians attitudes largely depend on gestational age. In fact as gestational age increases physicians' willingness to resuscitate also increases while as gestational age decreases their willingness to resuscitate decreases. However, a variety of attitudes was noticed at 23 and 24 weeks of gestation. Regarding the influencing factors, both physicians' demographic characteristics (e.g. religiosity, work setting) and case-related factors (e.g. condition at birth, birthweight, parents' requests, but also maternal demographic characteristics and fear for litigation) were found to be associated with physicians' attitudes. Reflecting on these results, the lack of agreement in the 23<sup>rd</sup> and 24<sup>th</sup> weeks confirms the existence of a grey zone of uncertainty in these weeks and the need for more ethical reflection on the management of EPIs born in the grey zone. Moreover, the fact that the majority of studies focused explicitly on attitudes according to gestational age suggests that gestational age is the main if not the only relevant factor for the decision. However, our results suggest that an interplay of different factors rather than gestational age alone influence physicians' attitudes. Therefore, more research investigating the impact of such factors is needed.

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Please read rules for abstract below*

**Submission by:**

**Submission by:**

Name: Dr Anne Bean; Dr Jennifer Peterson;

Institution: St Mary's Hospital, Manchester.

Speciality and Year: Neonates, ST8, ST5

Contact Address: Flat 19, The Slate Yard, 7 Stanley Street, Manchester. M3 5EX.

Email: [jennifer.peterson@hotmail.co.uk](mailto:jennifer.peterson@hotmail.co.uk)

Mobile: 07922864042

Wessex Trainee: No

**Submission for:** Both.

**Title:** When parents and clinicians disagree, first do no harm

**Authors:** Dr A Bean, Dr J Peterson, Dr Kristin Tanney; Dr Ranganath Ranganna

**Abstract:** (400 words)

The emotive cases of Charlie Gard and Alfie Evans have generated global commentary on the role and extent of parental responsibility. They served to highlight that, in the UK, parental responsibility is not an absolute right. Parents are acting as a proxy for their child; their view must promote their child's welfare. The vast majority of parents uphold their child's best interests, but occasionally this may not be the case, due to grief, faith, misinformation, or other issues.

Our NICU, like many others around the country, has had several recent cases where there has been disagreement between parents and clinical teams on which course of action constitutes the infant's 'best interests'. This has generated much discussion on how to achieve "best interest" in cases such as these:

1. Case One: Religious influence

Near-term infant with profound neurological impairment likely secondary to an antenatal event but without a unifying diagnosis. Her parents, who had strong religious faith, did not agree that her condition would likely be life-limiting, and struggled to come to terms with the suggestion of palliative tracheostomy.

2. Case Two: Religious influence

Preterm infant with severe HIE who had several failed attempts at extubation. Her parents had strong religious beliefs and did not wish to consider any limitations of treatment, or reorientation of care.

### 3. Case Three: Disengagement and Denial

Term infant with a hypomyelination disorder who was ventilator dependent. Parents found discussions regarding future plans challenging and often did not attend planned meetings.

When parents and clinicians disagree, parental responsibility may ultimately be overridden, but as some well publicised legal cases have illustrated, parental responsibility is rarely disregarded by the court, and only in cases with perceived significant burden of **harm**

In pursuing “best interest” for our vulnerable patients, there is occasionally a role for mediation, ethics committees or, in extremis, court. Best interests can be hard to define, whereas how to prevent *harm* is possibly easier to describe and achieve. It may be that this is the best outcome to strive for when unifying parents and clinicians in caring for their life-limited child.

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Please read rules for abstract below*

**Submission by:**

Name: Avineet Kaur

email: [avineet.kaur@nhs.net](mailto:avineet.kaur@nhs.net)

Institution: Luton and Dunstable University Hospital

Mobile: 07863742965

Specialty & Year: Paediatrics ST

Contact Address: Neonatal unit, Luton and Dunstable hospital, UK

**Submission for:** (Podium / Poster) **Both**

**Title:** Parental perceptions and best interest practice: The child at the centre.

**Author(s):** Dr Avineet Kaur, Dr Doris Wari-Pepple

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

**Background:**

*Female infant, 32+4 week gestation of consanguineous parents, born by elective caesarean section because of reduced fetal movements, growth restriction and oligohydramnios. She was born in a fair condition and was transferred to the neonatal unit requiring minimal respiratory support.*

*History of older sibling diagnosed with co-enzyme Q10(COQ10) deficiency postnatally with severe global developmental delay. Maternal uncle died at 2years of age due to COQ10 deficiency and a maternal aunt was reported to have died of unknown cause in the neonatal period. Both parents who carried an altered COQ9 gene declined antenatal screening in this pregnancy and were hopeful of a good outcome for her.*

*She subsequently developed metabolic acidosis after birth which worsened progressively with rising lactate levels despite commencing coenzyme Q10 and Idebenone replacement therapy within a few hours after birth. At 22 hours of age, her lactate levels became unrecordable (greater than 31), she developed multiorgan failure requiring increasing ventilatory support, multiple inotropes and multiple doses of bicarbonate infusions in attempt to correct the metabolic acidosis. She remained refractory to the COQ10 and Idebenone replacement therapy.*

*Her family had been counselled antenatally about the outcome, had multiple discussions and updates about her worsening clinical condition. They however refused to consider redirection of care. They felt that her older sibling with the disorder had survived, had a good quality of life and were hopeful that she would also.*

*The ethical challenge faced by the medical team was conveying the “no Chance” situation and how continuing intensive care was delaying death, not improving her suffering and wasn't in her best interest. It was difficult to reach a common ground with the family about the futility of prolonging treatment and their understanding of life's quality. It was distressing for the medical team to witness the futility of the treatments and how continuation wasn't in her best interest. Do parental perception of quality of life for their child translate to their child's interest?*

*At 72 hours of life, with lactate levels unrecordable for over 50 hours, multiorgan failure (acute kidney impairment, uncontrollable seizures, refractory hypotension and gut dysfunction) the parents finally agreed for withdrawal of intensive care and she passed away in her mother's arms.*

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# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

### Submission by:

Name: Dr Claire Caldwell  
Institution: Neonatal Unit  
St Thomas's Hospital, London  
Specialty & Year: ST8 Neonatal Grid Trainee  
Contact Address: 23 Meadlands Drive, Ham, TW10 7EF

email:clairecaldwell@hotmail.com  
Mobile: 07816 773688  
Wessex Trainee: No

**Submission for:** Podium/Poster (both)

**Title:** Withholding lifesaving treatment in a baby in non-critical condition: is it ethical?

**Authors:** Dr Claire Caldwell<sup>1</sup>, Dr Chirag Mehra<sup>2</sup>, Dr Chinthika Piyasena<sup>3</sup>, Dr Anna Paltrinieri<sup>3</sup>

<sup>1</sup> Neonatal Grid Trainee, <sup>2</sup> Paediatric Specialty Trainee, <sup>3</sup> Neonatal Consultants, St Thomas's Hospital

### Abstract:

We present the case of a baby postnatally diagnosed with Fraser syndrome. There was initial conflict between the parents and the medical team regarding the baby's best interests, and direction of care.

### Medical history

Antenatally, she was diagnosed with unilateral kidney agenesis. The parents had a previous termination of pregnancy for a foetus with bilateral renal agenesis. After delivery at term, she was noted to have dysmorphic features including fused eyelids, syndactyly and an anorectal malformation with a fistula. She was breathing without respiratory support, and was transferred to a surgical unit for further management.

### Conflict between parents and the medical team

Her parents' initial wishes, were to redirect care and transfer to a hospice. They thought it was appropriate to withhold life-saving treatment because her quality of life would be too poor, and that she would be frightened and alone, in a world of "silence and darkness". However, most senior medical staff thought it was in the baby's best interests to proceed with a colostomy formation, enabling her to feed and ultimately survive. With parental consent, parenteral nutrition was commenced on day five.

### Ethical aspects

Two main ethical problems emerged.

Firstly, this case illustrates the difference between withdrawing and withholding treatment. <sup>1</sup> Although both actions lead to the same outcome, medical professionals feel differently about them.<sup>2</sup>

Secondly, a 'best interests' debate: who decides the best interests of the baby? When and why is it appropriate for medical professionals to counteract the parents' wishes?

Ultimately, it is in the baby's best interest to survive, unless that life would be intolerable.

### Ethics committee

In view of this, the advice of the ethics committee was sought. They concluded there was no ethical justification for withdrawal of nutrition or to comply with the family's wishes not to form a stoma, as, "although the potential morbidity was tragic, the baby was not currently in the process of dying". However, they noted it may be ethical to limit the escalation of care in the future.

### Clinical course

During this process, the baby passed meconium via a fistula. The parents interpreted this as a sign of her desire to live, and subsequently consented to the stoma. Although she would be blind, she passed a hearing test, allaying some parental fears regarding sensory deprivation. She was discharged home after a month, and subsequently discharged from palliative care, although she continues to have medical and surgical follow up.

**References**

1. Larcher V, et al. Arch Dis Child 2015;100(Suppl 2):s1–s26. doi:10.1136
2. Nuffield Council on Bioethics. Critical care decisions in fetal and neonatal medicine: ethical issues. London: Nuffield Council on Bioethics, 2006

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**Submission by:**

Name: Erika Harterink-Rojas  
Institution: Poole Hospital Foundation Trust  
Specialty & Year: Paediatrics ST7 currently OOP  
Contact Address: 9 Endfield road, BH9 1TJ

email: [eerj73@yahoo.com](mailto:eerj73@yahoo.com)  
Mobile: 07917042485  
Wessex Trainee: Yes

**Submission for:** Podium and Poster

**Title:** Managing uncertainty in an end of life setting

**Author(s):** Harterink-Rojas E, Hussey M, Frost J, Keegan A, Tighe MP

**Abstract:**

History: We present a neonate with complex antenatally diagnosed cardiac abnormalities: (left ventricular hypoplasia and coarctation of the aorta) and IUGR. The family had received prenatal counselling and he was born by planned caesarean section at 37+5 weeks weighing 1.6kg. Postnatally he was found to have an undiagnosed genetic condition with multi-system involvement, with severe renal failure due to marked renal hypoplasia, microphthalmia, refractory hypoglycaemia, bilateral hip dislocation and ambiguous genitalia. Parents are biologically related and from Afghanistan, and have two healthy older sisters and a sister who unfortunately, passed away aged 2 years with renal hypoplasia, lung hypoplasia and microphthalmia.

Due to the underlying irreversible renal failure, cardiac surgery was deferred, with an advanced directive for comfort care agreed by parents and explained to them. He was transferred initially back to his local hospital then home, at parents' request with home oxygen (0.01-0.02l/min NPO2), buccal morphine and nasogastric feeds.

He is now 11 weeks old and remains stable. The family have declined further testing for him, after re-echo at 4 weeks confirmed the above findings with a minor PDA only and his U+E's remained very abnormal. Na 118, k 6.6 creatinine 147 and urea 13. However, his urine output is stable, and he has gained a small amount of weight (100g). The family continues to enjoy activities with him. They remain realistic, living day by day. They do not know how long he will remain alive.

**We welcome the opportunity to discuss**

The role of blood monitoring to help treatment (e.g. sodium supplements to help growth)

When would we contemplate further investigations?

Are we over-medicalising by weekly home visits?

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**Submission by:**

Name: Faezeh Sakhinia email: [faezehsakhinia@doctors.org.uk](mailto:faezehsakhinia@doctors.org.uk)  
Institution: St Helens and Knowsley Deanery Mobile: 07795384233  
Specialty & Year: Paediatrics, ST4 Wessex Trainee: No  
Contact Address: 16 Bloomfield Drive, Cheetwood, Manchester, M88ER

**Submission for:** Both

**Title:** When should we stop resuscitation of a neonate born with no cardiac output? A case report of a term infant with first audible heart rate at 23 minutes of life.

**Author(s):** Dr Faezeh Sakhinia (Paediatric ST4), Dr Archana Mishra (Neonatal Consultant)

**Abstract:**

Owing to concerns with high mortality and morbidity, current Neonatal Life Support (NLS) guidance on management of neonates born with no signs of life is to consider discontinuing resuscitation at 10 minutes of life if there is persistent absence of cardiac activity.

We present a case which highlights that it is time to reconsider this guidance. At a tertiary neonatal unit, a 38+6 week gestation male infant was born in poor condition following an emergency caesarean section with a background of reduced foetal movements and prolonged foetal bradycardia. With Apgar scores of 0 until 20 minutes of life, he was intubated and ventilated with cardiac compressions and resuscitation drugs were given. First detectable heart rate was auscultated at 23 minutes of life with first gasp noted at 28 minutes. He underwent 72 hours of therapeutic hypothermia with need for anti-convulsants in the first 24 hours of life due to electrical and clinical seizures. During this period, he developed disseminated intravascular coagulation (DIC) with renal and liver impairment which recovered by discharge. Although on admission his neurology and CFM monitoring was in keeping with severe hypoxic ischaemic encephalopathy (HIE), the clinical and CFM findings improved on day two. He was extubated on day five of life and on discharge at two weeks of age, he was self-ventilating in air and demand breast feeding. MRI scan of his brain on day six of life did not identify any radiological features of HIE. Apart from mild hypotonia, the rest of his neurology was normal on discharge.

This case supplements growing evidence for the need to continue resuscitation beyond current guidance of 10 minutes. Recent literature review shows increase in survival without neurological morbidity in around 50% babies with an Apgar score of 0 at 10 minutes.

Ethically, we propose that resuscitation attempts should be extended for 25-30 minutes of life to provide every chance for similar neonates as our patient. We also propose a national registry of babies needing extensive resuscitation at birth and no cardiac output at 10 and 20 minutes of age as outcomes may be improving over the last decade since the adoption of therapeutic hypothermia for babies with HIE as advocated by NICE guidance in 2010.

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## European Neonatal Ethics Conference 2019

### Oral or Poster: Abstract Submission

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#### **Submission by:**

Hushi Hu, ST6 Neonates (Wessex), Neonatal Intensive Care Unit, Queen Alexandra Hospital, Portsmouth  
Email: hushihu@googlemail.com Mobile: 07742 711616

**Title:** Severe Bronchopulmonary Dysplasia - Dilemmas Around Continuing Long-Term Intensive Care

**Authors:** Hushi Hu, Tim Scorrer, Richard Thwaites

#### **Abstract:**

We present a case illustrating the increasingly common but complex neonatal dilemmas surrounding babies requiring prolonged intensive care.

#### **Case:**

J was born at 26 weeks' gestation on a background of maternal chorioamnionitis and prolonged rupture of membranes for nine weeks. Parents were counselled antenatally about the likelihood of significant pulmonary hypoplasia.

J had a stormy postnatal course; developing severe bronchopulmonary dysplasia, significant pulmonary hypertension and patent ductus arteriosus judged unsuitable for surgery. He remained ventilator and sildenafil dependent at term corrected. He had difficult intravenous access, multiple episodes of sepsis and laser treated retinopathy of prematurity. MRI revealed large parenchymal cysts in the posterior parietal lobes, although precise prognostication was difficult. Clinically, he had immature visual development, but grossly normal neurology and positive interactions.

Aged term corrected, J developed an incarcerated inguinal hernia and was transferred to a surgical neonatal unit for an uncomplicated mini-laparotomy. A joint neonatal/cardiac multidisciplinary team meeting was convened four days post-operatively, as clinicians there felt his lung disease was end-stage, prognosis poor and questioned the appropriateness of continuing intensive care. Parents were presented with a view that continuing intensive care would not be in his best interests. Parents requested a transfer back to his original neonatal unit, where they felt more familiar, for further discussion regarding direction of care.

On transfer back, although acknowledging the challenging outlook, parents wished to continue intensive care, to trial extubation and have more time to process information. This course was supported by the local team. J was successfully extubated five days later. He continued to have significant oxygen requirements and was transferred aged six months for paediatric respiratory assessment for long term non-invasive ventilation. A prior paediatric neurology review confirmed no contraindication to this. J remained in hospital for a further three months. He was discharged home aged nine months with oxygen, nocturnal CPAP and nasogastric feeds.

Aged 18 months corrected, he continues on oxygen, nocturnal CPAP and gastrostomy feeds. He has global developmental delay, especially visual impairment, but is progressing with multidisciplinary support.

#### **Ethical dilemmas highlighted:**

##### *Best interests*

- Benefits and burdens of prolonged intensive care for baby, family, staff and wider population.
- Difficulty predicting outcomes and defining quality of life.

##### *Decision making process*

- Complex – series of difficult decisions/conversations over time.

##### *Multidisciplinary and multi-centre involvement*

- Breath of experience and perspectives.
- Challenges: conflicting opinions, consistent/clear communication, family-professional relationships.

##### *Conveying information*

- Timing, context and delivery of difficult conversations can be influential.

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Please read rules for abstract below*

### **Submission by:**

Name: Jennifer Peterson

Institution: St Mary's Hospital, Manchester.

Speciality and Year: Neonates, ST5

Contact Address: Flat 19, The Slate Yard, 7 Stanley Street, Manchester. M3 5EX.

Email: [jennifer.peterson@hotmail.co.uk](mailto:jennifer.peterson@hotmail.co.uk)

Mobile: 07922864042

Wessex Trainee: No

### **Submission for:** Both.

**Title:** Congenital Diaphragmatic Hernia and FETO: The Ethical Issues.

**Author:** Dr J Peterson and Dr S Kamupira.

### **Abstract:**

Baby T was antenatally diagnosed with an extensive left sided congenital diaphragmatic hernia. Parents were well informed, and learnt about the London FETO trial and wanted to participate.

Baby T underwent fetoscopic tracheal occlusion treatment (FETO). The pregnancy continued and the balloon was electively removed at 36weeks gestation. Labour occurred spontaneously at 37weeks gestation.

T was born in poor condition. He was intubated on first attempt and responded well to initial resuscitation. However, as expected, oxygenation was problematic from birth. He was commenced on HFOV and iNO. He received multiple inotropes but despite this his oxygenation did not improve and his blood pressure continued to deteriorate. It was not felt that ECMO would be appropriate or beneficial. He passed away in his parents arms in the bereavement suite.

### **The Ethical Issues:**

1. Fetal surgery is an emerging field with multiple new ethical issues. In UK law the unborn fetus has no rights. To operate on a medically-well mother for the exclusive benefit of her fetus, exposes her to medically 'unnecessary' risk. The procedure is undoubtedly being done for the fetus' benefit, which would seem to acknowledge the fetus as a distinct entity with an intended future. Acknowledging the fetus' interest in having the best health for their future seems at odds with the current UK legal position that fetuses have no rights at all until they are 'fully delivered of their mother'.

2. Procedurally, if the fetus delivers with the balloon in-situ it will be unable to breathe or be intubated until the balloon is removed. Parents generally remain in the FETO centre for only 1-2 days post-procedure. There is ethical concern that if preterm labour occurs (as can happen following FETO or simply due to congenital abnormalities) and the baby delivers in a centre not accustomed to FETO balloon removal, this could worsen the outcome.

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Please read rules for abstract below*

### Submission by:

Name: Nora Tusor (on behalf of Karen Turnock)

email: [nora.tusor@kcl.ac.uk](mailto:nora.tusor@kcl.ac.uk)

Institution: Evelina London Children's Hospital

Mobile: 07508864855

Specialty & Year: consultant

Wessex Trainee: ~~Yes~~ / No

Contact Address: Neonatal Unit, North Wing 6<sup>th</sup> Floor St Thomas' Hospital, Westminster Bridge Road, SE1 0EH

**Submission for:** ~~Podium / Poster~~ / Both (delete as appropriate)

**Title:** Thinking, saying and doing: an observational study of intervention and outcome for children with trisomy 13 or 18 admitted to a single centre

**Author(s):** Karen Turnock, Sarah Burnett, Katherine Styles, Nora Tusor

### Abstract:

Background: Clinicians endeavour to share decision making with parents. However, this can be challenging in complex cases, when clinicians' expectations for the child differ from parents' wishes. We describe a cohort of children with trisomy 13 or 18 (T13/T18) whose parents sought active medical treatment. Medical professionals may find themselves in moral distress at providing intensive care in such cases, whilst the children's parents might not perceive the futility of such care.

Aim: Our aim was to define the clinical pathway up to the point of genetic diagnosis, perinatal clinical management and outcome in a cohort of children with T13/T18 where parents sought active postnatal management.

Methods: We prospectively collected and retrospectively analysed perinatal clinical data of infants with ante- or postnatal diagnosis of T13/T18 who were admitted to our Neonatal Unit between 04/2010-03/2019. Pregnancies discontinued because of a genetic diagnosis were excluded.

Results: Twenty-six children were identified, (n=10 male, n=16 female). Twenty (77%) children had a genetic diagnosis of T18 and 6 (23%) T13. Median (range) gestational age was 35<sup>+6</sup> (27-41) weeks. Nineteen infants were born in our hospital (n=13 T18, n=6 T13), and 7 were transferred postnatally. All 5 (19%) infants with an antenatal genetic diagnosis were born at our centre (n=3 T18, n=2 T13). Parents declined invasive antenatal testing in 13 (50%) cases with significant anomalies (n=4 T13, n=9 T18). Other antenatal findings included growth restriction (n=4) and/or polyhydramnios (n=2). One pregnancy was not booked, and 1 was booked late with no anomaly screening. Only 1 pregnancy was uncomplicated. Five (19%) mothers had a normal delivery. Twenty-one (75%) infants were born by lower-segment caesarean section (LSCS) (elective/semi-elective n=10, emergency n=11). Three infants who were born by emergency LSCS had an antenatal diagnosis and 3 had significant anomalies. During delivery room stabilisation, 10 (38.5%) infants were intubated and 5 (19%) received non-invasive respiratory support, including one in each group with an antenatal genetic diagnosis. Median (range) age at death was 29 (1-798) days for the 24 (92%) children who passed away.

Conclusion: The advent of antenatal genetic testing assumed parents would discontinue the pregnancy in case of T13/T18, or if continue accept the risk of stillbirth and engage with palliative care postnatally. Although, our data demonstrates that not all parents wish to follow these pathways we believe medical professionals should continue to strive for shared decision making, support colleagues and parents, whilst advocate in these children's best interest.

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Please read rules for abstract below*

**Submission by: Linden Stocker**

Name: Linden Stocker

Institution: University of Southampton

Specialty & Year: O&G ST7

Contact Address: Room F89, Princess Anne Hospital, Coxford Road, SO16 5YA

Email: [l.stocker@soton.ac.uk](mailto:l.stocker@soton.ac.uk)

Mobile: 07515798116

Wessex Trainee: Yes

**Submission for:** Both

**Title:** What should we do in anomaly-discordant twin pregnancies when there is a life-limiting condition affecting one baby?

**Author(s):** Linden Stocker, Tara Bharucha, Colette Cochran, Rajeswari Parasuraman

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

**History:**

A patient of Chinese origin was seen in Fetal Medicine with Monochorionic Monoamniotic twins. One twin had a normal heart, the other a hypoplastic left heart variant. Imaging was suboptimal but it was thought the postnatal systemic circulation would be duct-dependent. Parents were counselled that the affected baby had a life-shortening condition, and was unlikely to survive without medical/surgical intervention. The parents were offered selective termination or continuation of pregnancy with either postnatal surgical palliation or comfort care. The family opted to continue, avoiding risk to the unaffected twin, and postnatal comfort care.

Both twins, born at 33 weeks, required routine neonatal unit admission. Postnatal imaging confirmed a hypoplastic left heart variant with a balanced circulation which was not duct-dependent. The baby was likely to survive several months or longer without intervention. The parents were reluctant to consider discharge home of both twins together. They expressed a desire to respect their own parents' cultural belief that contact between the twins would be detrimental to the unaffected baby. There could have been conflict between the family and the caring team due to differing views regarding appropriateness of surgical intervention. This was avoided by careful counselling and respectful acknowledgement of opposing views. The parents wished to act in both babies' best interests. By time of discharge the family were comfortable proceeding to cardiac surgical treatment.

**Ethical conundrum:**

What should we do in anomaly-discordant twin pregnancies when there is a life-limiting condition affecting one baby? How is it best to approach these families and explore their ethical/cultural values?

Challenges in this case involved provision of value-neutral counselling and identifying the family's beliefs. Offering surgery or trial of therapy for an infant with a low chance of survival may be appropriate. However, if adequate institutional/population-based data demonstrate futility of intensive care in supporting long-term survival, it may be ethically permissible, or even obligatory, to offer only comfort care to the baby. Counselling about treatment options available is an important component of antenatal care in complex pregnancies.

**Outcome:**

Parents sometimes make the difficult decision to refuse palliative surgery in order to limit perceived or expected suffering. Medical teams looking after the infant would support parents throughout this decision-making process. Should healthcare teams and families differ in views regarding appropriateness of medical/surgical intervention, there is potential for conflict, occasionally requiring intercession via the legal system. Respectful counselling can avoid conflict, and lead to favourable patient and family outcomes.

Word count 399

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Please read rules for abstract below*

**Submission by:**

Name: Lindsay mulligan

email: [Lindsaymulligan@hotmail.com](mailto:Lindsaymulligan@hotmail.com)

Institution: UHCW

Mobile: 07834315783

Specialty & Year: ST4 Paediatrics

Wessex Trainee: No

Contact Address: UHCW Neonates, Clifford Bridge Road, Coventry

**Submission for:** Podium / Poster / Both

**Title:** Logistics of neonatal organ donation in anencephaly

**Author(s):** Lindsay Mulligan, Karen Otty, Priya Parthasarathy, Prakash Satodia, Arthi Lakshmanan

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

Background: In the UK there are currently 184 paediatric patients on the transplant list, over 90% of which are waiting for either a heart, kidney or liver. In the paediatric population, the need for these organs has consistently exceeded the number of organs available. The UK Donation Ethic Committee (UKDEC) define death as the irreversible loss of the capacity for consciousness combined with the irreversible loss of the capacity to breathe. Organs can be 'donated after circulatory death' (DCD) or 'donated after brain death' (DBD). Brain death is diagnosed using specific neurological criteria that has been validated for use in infants >37 weeks corrected gestational age and up to two months of age. Circulatory death is diagnosed after five minutes of continuous cardio-respiratory arrest, with subsequent absence of brain-stem function and reflexes.

Case report: Although there have been several successful organ donations from neonates with life limiting conditions, there are multiple ethical and logistical considerations that need to be evaluated prior to donation. This is a review of a recent case of a fit and well gravida 2 para 1 mother, where the fetus was diagnosed with anencephaly at the dating ultrasound scan. The mother was offered a termination of the pregnancy, which she declined. She continued with the pregnancy and following counselling wanted to donate her baby's organs. This set in motion a series of ethical and logistical conundrums.

Ethical and logistic considerations: The window for DCD being only 5 minutes for liver donation, it caused a dilemma of how to effectively monitor the child without hindering the parents' experience of spending precious moments with their child. This was a planned caesarean section for maternal reasons which helped in ensuring the appropriate teams would be present and parallel theatres open for delivery and organ retrieval, which would have been difficult if it was a vaginal delivery. Several counselling sessions were planned for the parents with multiple teams to ensure they fully understood what would happen and were in full agreement. Unfortunately organ donation was not ultimately possible due to a viral infection in mum but this led to major team learning about neonatal organ donation and the framework to approach it.

Discussion: This case review covers the key ethical and logistical issues encountered and learning points for the fetal medicine and neonatal teams for future potential neonatal organ donation.

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Please read rules for abstract below*

**Submission by:**

Name: Natasha Jones

email: [JonesN64@cardiff.ac.uk](mailto:JonesN64@cardiff.ac.uk)

Institution: Cardiff University

Mobile: 07530333395

Specialty & Year: Year 3 Medical Student, SSC in Paediatric Palliative Care

Wessex Trainee: No

Contact Address: 6 Edgecumbe Rd, Bristol, BS6 7AX

**Submission for:** Poster

**Title:** An evaluation of Advanced Care Planning use for neonates in the Paediatric Palliative Care service in Cardiff and Vale University Health Board

**Author(s):** N. Jones, T. Warlow

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)*

*(Please consider case history, ethical conundrum, outcome for the cases)*

**Objective;** To assess the quality of Advanced Care Planning in neonates with palliative care needs referred to the All Wales Paediatric Palliative Care Service

**Background;** Advanced Care Planning (ACP) is one of the key principles of good practice within children's palliative care. ACP is a process of discussion between an individual and their care provider regarding wishes for the child, in addition to end of life care and some aspects following death. Alongside ACP, parallel planning, planning for babies lives whilst also being prepared for deterioration or death, is a vital part of managing difficult cases, often involving complex ethical issues and decision making. The process of writing a care plan or end of life plan aims to facilitate family wishes being respected where possible, in regards to those elements of the child's care that can be controlled.

**Methods;** Retrospective audit of data collected from Welsh Clinical Portal and Ty Hafan Children's Hospice archives between January 2015 and December 2018. Patients were neonates under the palliative care team in the Cardiff and Vale area who had died before their first birthday. Current guidelines on ACP were taken from NICE, Royal College of Paediatrics and Child Health and Together for Short Lives, a charity specialising in palliative paediatrics.

**Results;** Data from 26 patients was used in the final audit and analysed. 34.6% of these engaged in formal paediatric advanced care planning (PAC-planning), including completion of a written plan serving as a template for discussions with parents. However, a similar percentage engaged in informal discussions that still achieved many of the same criteria. Many aspects of ACP were demonstrated to have been done well, for example, complying with families' wishes for place of death was achieved 83% of the time, however a number of guidelines were poorly adhered to, for example documentation of discussions regarding organ donation or religious preferences were available in less than 25% of patients. Data highlighted that a stay at Ty Hafan children's

hospice had a significant impact on the quality of record keeping and whether the families received extensive holistic support.

*Conclusions;* Completion of advanced care planning is variable with low rates of PAC plan completion. However, many discussions of complex cases do occur informally. Recommendations include: adapting the current PAC-plan tool to keep up with current guidance and improving the documentation of care planning discussions.

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**Submission by:**

Name: Rashmi Mehta

Institution: University Hospitals of Birmingham (Heartlands)

Specialty & Year: ST6 Neonates

Contact Address: 14 Laxton Grove, Solihull, B912JT

email: rashmi.mehta1@nhs.net

Mobile: 07946603839

Wessex Trainee: No

**Submission for:** Both (Podium and poster)

**Title:** 23 weeks on dot. Being born at the edge of viability.

**Author(s):** Rashmi Mehta (ST6)/ Victoria Fradd (Consultant Neonatologist)

**Abstract:**

*(Please consider case history, ethical conundrum, outcome for the cases)*

**Case history:**

A 23 week neonate was born with weight of 540grams. Antenatal counselling was done in keeping with BAPM (British Association of Perinatal Medicine) guidance (Wilkinson et al 2008). RCOG/ NICE guidance in relation to steroid or magnesium sulphate administration in mothers of 22-23+6 gestation is unclear. In cases as such, the neonatologist is asked whether a mother should receive steroids and magnesium sulphate. In this case the mother was in established labour and delivered the infant before the drugs could be administered. He responded with increase in heart rate to respiratory intervention and was transferred to the unit.

**Ethical conundrum:**

Over a period of time we have stretched the limit of viability. We strive between hope and verity, between optimism and realism. The outcome, though improved in other countries, the data quoted in antenatal counselling is mainly from the EPICure (1995, 2006) study.

There is significant mortality and morbidity associated with extreme preterm births. There are pertinent questions which we should deliberate as we counsel the parents and manage this group of infants even though the opinions vary widely amongst our colleagues.

Are we optimising the antenatal care with steroids and magnesium sulphate as the predictability of delivery is uncertain and likelihood of delayed delivery with chance of needing second doses of drugs would be still a plausible one? As these babies survive and leave neonatal units, do we have enough resources in community to support them and their families? As medical society do we have a myopic view or are we looking at measures to strengthen our resources to support them in community and their morbidities abutted in the realms of primary, secondary and tertiary care which they frequent through the rest of their lives? Are we in a vicious cycle of self fulfilling prophecy where our data in relation to morbidity and mortality is unlikely to improve as we don't optimise the antenatal care or their resuscitation at birth?

**Outcome:**

As we write this abstract, the infant is 6 weeks old, growing between 9th and 25th centile on full enteral feeds with no intraventricular haemorrhage. An attempt to take the infant off the ventilator was unsuccessful at nearly 4 weeks of age after a DART (Dexamethasone: A Randomised Trial) regime of steroids. We await his growth on ventilator, plan to give second course of steroids and attempt to extubate in near future.

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*Please read rules for abstract below*

Submission by:

Name: Rashmi Mehta

email: [rashmi.mehta1@nhs.net](mailto:rashmi.mehta1@nhs.net)

Institution: West Midland Deanery Paediatrics

Mobile: 07946603839

Specialty & Year: ST6 Paediatrics

Wessex Trainee: No

Contact Address: 14 Laxton Grove, Solihull, B912JT

Submission for: Both- Podium and Poster

**Title:** Ethical Dilemma Posed by Geographical Movement of Roma Community.

**Author(s):** Mehta R<sup>1,2</sup> Gowda H<sup>1</sup>

1 University Hospitals Birmingham (Heartlands)

2 Birmingham Women's and Children's Hospital

### **Abstract:**

Case history:

A late preterm infant of young non-consanguineous Roma parents was born with antenatal diagnosis of TMEM70-gene mutation. Parents were homozygous carriers and an affected sibling died at 25 days of life. TMEM70-gene mutation is associated with mitochondrial complex-V deficiency leading to encephalocardiomyopathy, a life limiting condition. At antenatal counselling, after discussion, a mutual decision was made for mother and baby to stay together in bereavement-suite. However after baby's birth, parents wished for full treatment and admission to Neonatal Intensive Care Unit (NICU).

Ethical conundrum:

We live in a diverse multicultural society as global citizens, sharing health care services. As part of the 'geographical movement' Roma Gypsies bring in their own beliefs and cultures.

Would ideas and beliefs around the 'end of life (EOL) care', which they trusted and practiced, change as they migrate?

Particularly relevant to the Roma community, surfacing conflicts making palliative care discussions challenging are, lack of autonomy and decision making power. Decisions are usually taken by head of the family. Family plays preponderating role in providing major support during illness. They perceive illness with shame, consider death impure and are reluctant to make decision to stop life prolonging treatment. Often there is scepticism towards health care professionals, with antecedent beliefs that treatments may be labelled futile to save money. (Roman G et al 2014).

However was it ethical to offer intensive care to baby, who otherwise has life limiting condition? This not only led to medical intervention but also separation of mother and baby during baby's dying hours.

Cases which pose ethical dilemma, various philosophies of ethics are considered. In this particular case, approach solely based on 'Teleology' - rightness or wrongness based on the good or bad consequences or 'Deontology' - based on moral duties, would be difficult. However it can be better explained using concept of 'Communitarian Ethics' - influence of community on the individuals and values based on traditions and culture. (Brannan S et al 2012).

#### Outcome:

Parents' wishes were honoured and baby was admitted to NICU. Parents' along with their family, often need time in making decisions towards 'EOL care'. Respecting parents' cultural beliefs and recognition that in certain communities concept of palliation is not well established, is of paramount importance. Repeated conversations over a period of time builds trusting relationship. At the heart of these conversations one should keep the best interests of the baby. Baby was supported with nasogastric-tube feeding and commenced on dichloroacetate for lactic-acidosis. Baby died on third day of life.

#### Reference:

1. Brannan S, Chrispin E, Davies M, English V, Mussell R, Sheather J, Somerville A (2012) Medical Ethics Today, BMA's Handbook of Ethics and Law, West Sussex, 3rd Edition.
2. Roman G, Gramma R, Enache A, Pa<sup>^</sup>rvu A, Ioan B, Moisa S, Dumitras S, Chirita R (2014) Dying and Death in Some Roma Communities: Ethical Challenges J Immigrant Minority Health 16 :290–300

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Please read rules for abstract below*

**Submission by:** Name: Rebecca Greenberg RN, PhD email: [rebecca.greenberg@sinaihealthsystem.ca](mailto:rebecca.greenberg@sinaihealthsystem.ca)

Institution: Mount Sinai Hospital & Department of Paediatrics, Faculty of Medicine, University of Toronto

Mobile: 1-647-866-6089

Specialty & Year: Bioethics (Doctorate of Philosophy (Bioethics) 2008)

Wessex Trainee: No

Contact Address: Bioethics Department, Mount Sinai Hospital, 600 University Ave, Toronto, ON M5G 1X5, Canada

**Submission for:** Podium / Poster / Both (delete as appropriate)

**Title:** Building Interprofessional Bioethics Capacity in the Neonatal ICU: a program of bioethics support in paediatric critical care

**Author(s):** Rebecca Greenberg

### **Abstract:**

The complexity of critical illness, technological capability, and societal expectations has inherent ethical challenges for paediatric critical care providers and has the potential to create significant moral distress. We report on the role of a bioethics service initiative to build capacity to address ethical issues and moral distress in 3 paediatric critical care units (neonatal, cardiac and pediatric) within one children's hospital. Each unit has its own 'ethical culture' – we share reflections on working in these unique settings. Care And Reflective Ethics Dialogue (CARED) – was developed to enhance provider awareness of ethical dilemmas and improve integration of ethics capacity into daily practice.

As it can be challenging to step away from the bedside for many practitioners, CARED provides ethics resources to be brought to frontline staff with an opportunity to interact with a bioethicist and work interprofessionally to identify ethical issues for later discussion or follow up. As a weekly event, the bioethicist speaks with frontline staff to take the 'ethics pulse check'. Following this a brief and confidential interaction with providers determines if an opportunity to discuss and reflect on difficult ethical dilemmas would be beneficial to the situation, individual, team or patients and families. Next steps include multidisciplinary case discussions, formal and informal education and/or debriefs. CARED facilitates interprofessionalism as it aims to bring staff from different disciplines together to support each other in working through ethical dilemmas.

Since the implementation of CARED, bioethics consultations, debriefs and formal and informal education initiatives have significantly increased in all three environments.

This presentation will: 1) explore challenges and opportunities for building ethics capacity in the Neonatal ICU environment; 2) discuss strategies to increase ethics capacity and buy-in in the Neonatal ICU environment.

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**Submission by:** Name: Rebecca Greenberg RN, PhD email: [rebecca.greenberg@sinaihealthsystem.ca](mailto:rebecca.greenberg@sinaihealthsystem.ca)

Institution: Mount Sinai Hospital & Department of Paediatrics, Faculty of Medicine, University of Toronto

Mobile: 1-647-866-6089

Specialty & Year: Bioethics (Doctorate of Philosophy (Bioethics) 2008)

Wessex Trainee: No

Contact Address: Bioethics Department, Mount Sinai Hospital, 600 University Ave, Toronto, ON M5G 1X5, Canada

**Submission for:** Podium / Poster / Both (delete as appropriate)

**Title:** Moral Distress in Paediatric Critical Care: Developing Strategies from Experience

**Author(s):** Rebecca Greenberg, Karen Dryden-Palmer, Andrew Hellmers

### **Abstract:**

*Background:* Moral distress was first described by Jameton in 1984, and has been defined as the distress experienced by an individual when they are unable to carry out what they believe to be the right course of action because of real or perceived constraints. This complex phenomenon has been studied in different groups of healthcare providers, with intensive care professionals in particular reported to experience higher levels of moral distress. This in turn has been implicated in burnout and its associated consequences such as job attrition. Indirectly, patients and their families thus bear a large part of this burden.

*Research aim:* There is a paucity of literature exploring how mid and late career healthcare providers cope with their moral distress; our study explores the experience of moral distress in this demographic, and the strategies and resources invoked to mitigate this distress.

*Research design:* We report a qualitative study involving focus groups and semi-structured interviews.

*Participants and research context:* Senior pediatric intensive care front line providers in a tertiary pediatric hospital.

*Findings:* Participants reported experiences of moral distress concordant with the literature, and identified strategies for positive adaptation including active, reflective and structured supports.

*Discussion:* Participants endorsed perspective-building and a movement towards formal supports; this resonates with the current literature in addition to opening up new avenues to explore in the management and mitigation of moral distress.

*Conclusion:* This exploratory study lays the groundwork for interventions that facilitate personal growth and meaning in the midst of moral crises in critical care practice.

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Abstracts can consist of the following

1. Work focussing on neonatal ethical conundrum
2. Interesting cases which allow for panel discussion amongst the delegates
3. Epidemiological studies/data raising interesting ethical questions
4. Research in the field of ethics with implications for neonatal care

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***There will be an award for the Young Investigator, Best oral presentation and Runner up.***

***There will also be a poster award.***

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

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conference booklet. Please return as a word document by email to [mproveonline@gmail.com](mailto:mproveonline@gmail.com)  
Please read rules for abstract below*

**Submission by:**

Name: Samantha Bend

email: [samantha.bend@elht.nhs.uk](mailto:samantha.bend@elht.nhs.uk)

[jasim.sim@gmail.com](mailto:jasim.sim@gmail.com)

Mobile: 07711787381

Institution: East Lancashire NHS Trust

Specialty & Year: ANNP

Wessex Trainee: No

Contact Address: NICU, East Lancashire NHS Trust, Casterton Avenue, Burnley

**Submission for:** Podium / Poster / Both

**Title:** Parallel Planning in Twin Pregnancy Antenatal Counselling and Implications at Delivery

**Author(s):** Samantha Bend, Jasim Shihab

**Abstract:**

**Introduction:** Palliation of care due to antenatal diagnosis of life threatening complications is often fairly straight forward. Antenatal counselling is provided and everybody involved knows what to expect. This process can be complicated when this involves a twin pregnancy. The following case study will be discussed to highlight ethical dilemmas that were faced at delivery when presented with a case where one twin was viable and one was deemed not.

**Case history:** Mum was a primigravida with no notable past medical history. Parents were non consanguineous and of Eastern European decent. She had a natural conception of MCDA twins. Antenatal scans showed twin 1 was developing normally but multiple abnormalities were noted in twin 2 including possible right diaphragmatic hernia and double outlet right ventricle and growth restriction. Antenatal counselling was performed with parents by the fetomaternal, neonatal and pediatric cardiac consultant. Parents wanted palliation of the twin with the congenital deformities. It was decided that twin one was for full normal resuscitation and twin 2 was for palliation of care. Elective caesarean done at 30+ 4 weeks for normal twin to have better prognosis.

**Delivery:** At birth, both twins were stable on PEEP with minimal oxygen requirement. Father was shown both the twins and we counselled him regarding X raying the possible twin with congenital anomalies and then deciding on further course of action. Xray showed a possible eventration/ diaphragmatic hernia. Father was spoken to and as the baby with the condition was stable, he wanted to continue full neonatal care. The twin was ventilated and then transferred to the neonatal unit.

Course:

Baby with deformities had a protracted course and passed away at 112 days. The other twin is doing well.

**Ethical Discussions:** Should delivery be done under ultrasound guidance in these situations, where one twin is for palliative care? Should a parallel planning discussion for intubating both twins at delivery (in view of the antenatal diagnosis of diaphragmatic hernia) have been done in such situations? If done then wouldn't the good twin be getting intubated unnecessarily?

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Please read rules for abstract below*

**Submission by:**

Name: Dr Sonia Goyal  
Institution: Heartlands hospital,  
Specialty & Year: Paediatrics, ST4  
Contact Address: Neonatal Department  
Heartlands hospital, Birmingham University Hospitals  
Birmingham  
United Kingdom

email: [kavelgoyal@hotmail.com](mailto:kavelgoyal@hotmail.com)  
Mobile: 07969657379  
Wessex Trainee: No

**Submission for:** Both

**Title:** Lotus birth: Ethical dilemma!

**Author(s):** Sonia Goyal, Harsha Gowda

**Abstract:**

*(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)  
(Please consider case history, ethical conundrum, outcome for the cases)*

**Background**

The 'Lotus Birth' is defined as not cutting or clamping the cord and placenta remains attached to the infant until it separates naturally. This is also termed as 'Umbilical nonseverance' or 'Physiological cord clamping (PCC)' There is a theoretical risk of infection to the infant, but severity is unknown. The closest comparable data will be on omphalitis (incidence of 1/1000) in developed countries.

With this background we report a Case of 'Lotus birth' where infant needed admission to the neonatal unit. We went through ethical dilemma in dealing with the situation as there are no national or international guidelines and sparingly available literature.

**Case report**

A term infant was born normally following 29 hours of premature rupture of membrane. Infant was born in good condition. Parents wanted 'Lotus Birth' therefore, cord was not cut. Infant developed tachypnoea at about 8 hours of age and required oxygen to maintain saturation therefore, needed admission to the neonatal unit. Parents refused to cut the cord, so, infant had to come to the neonatal unit with the placenta. There was a risk for infection to the infant and to the other infants on the unit as the placenta was entering the neonatal unit. Parents initially refused to commence the infant on the antibiotics but later agreed after discussions with neonatal team. Parents were applying rose petals and lavender oil to the placenta. Following the advice from hospital infection control team, infant was shifted to the side room as the placenta was an active source of infection and to avoid risk of infection to other infants. Infant was self-ventilating in air by 20 hours of age. Infant received 5 days of antibiotics and was discharged home on day 7 with placenta attached. No placental swab was sent.

**Conclusion**

This situation posed an ethical dilemma for us while counselling parents as there is no evidence-based research. What are the potential risks for this infant and to the other infants in the neonatal unit? To deliver a patient-centred care and accommodate family wishes, it must be medically safe. This case report highlights the need for an Internationally agreed guideline in managing such although uncommon but potentially challenging situation.



**Submitted by:** Shahzad Khattak ST5

Email: [shahzad\\_gul\\_khattak@yahoo.com](mailto:shahzad_gul_khattak@yahoo.com)

Mob: 07466441663

**Institution:** Neonatal Intensive Care Unit, Luton & Dunstable University Hospital

**Authors:** S. Khattak, B. Vakharia, J. Egyepong

**Submission for Both Podium and Poster.**

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**Abstract: Case Report & Associated Ethical Issues.**

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**Background:**

- GM1 gangliosidosis is an inherited disorder (Autosomal Recessive) that progressively destroys nerve cells in brain and spinal cord. Incidence is 1 in 100,000 to 200,000 newborns.

**Case History:**

- Case of an extremely preterm, born at 25+5 weeks weighing 930 grams.
- Family history: Elder sibling diagnosed with GM1, died aged 2 years.
- Both parents were found to have heterozygous GM1 mutation.
- Genetic bloods sent after birth.
- Required intubation and ventilation. Subsequently there were attempts to extubate but there were profound apnoea's needing reintubations.
- Clinical seizures presenting with apnoea from 3wks, started on Levetiracetam.
- Developed necrotizing enterocolitis at 4wks of age and transferred to first surgical NICU. Required minimal small bowel resection with jejunal stoma formation. Following surgery, developed proximal jejunal obstruction.
- Failed multiple attempts at extubation.
- **Genetic result confirmed GM1 at this stage.**
- MDT (Neonatologist, Surgeons, Geneticist, Palliative Care and Metabolic) discussion with Parents: In view of confirmed GM1, failure at multiple extubation attempts, post-NEC Jejunostomy with proximal jejunal obstruction, TPN-dependence, slowly worsening TPN-hepatitis features, ongoing seizures, it was agreed that redirection of care was in the best interest of the baby. Although surgeons were happy to fix his obstruction, parents not in favour of further surgery.
- MDT Plan: Transferred back to the local tertiary NICU to re-direct care- Palliative Care Pathway/ DNAR put in place

**Management on Local NICU**

- Successfully extubated on day 14 of return with slow step-down in respiratory support (RS) to Nasal 0.12l/min within 4 weeks of readmission.
- Second MDT held due to: Improvement in RS and parent's desire to take Baby home without a stoma or TPN/Longline
- MDT discussions with a different Surgical NICU & Teams (Surgeons, Neonatologist, Anaesthetist, Metabolic, Palliative Care and Gastro): Raised **ethical dilemmas**: Will require upper and lower GI contrast, laparotomy, placement of paediatric PICC, re-intubation and ventilation and is successful extubation likely after?
- Had assessment followed by reversal of the stoma, replacement of neonatal with paediatric PICC

**OUTCOME OF THE CASE:** Underwent stoma reversal, achieved enteral feeding (NGT mainly and some bottle), TPN-hepatitis resolved and went home on NC oxygen.

**ETHICAL CONUNDRUMS:**

1. How far in terms of management, should a team go in short life-limiting cases such as GM1 or with a similar case?
2. Was the decision of not relieving jejunal obstruction and DNAR initiated too early at first surgical NICU?
3. Above questions also raises issues involving counterfactual reasoning, hindsight and outcome bias.

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

**Submission by:**

Name: Heather Sharon Hodgson  
Institution: Community Child Health, Virgin Care Ltd  
Specialty & Year: ST4 Community Paediatrics  
Contact Address: 4 Otter Way, Thornbury, BS35 1AE

email: s.hodgson1@nhs.net  
Mobile: 07899975960  
Wessex Trainee: No

**Submission for:** Poster

**Title:** Who can give consent? A Survey of Paediatricians knowledge about consent for babies born following surrogate pregnancies

**Author(s):** Heather S Hodgson, Abigail Nye, Fiona Finlay

**Introduction:**

Surrogacy involves an agreement between a third party (the Intended Parents (IP)) and a woman, that she will become pregnant with the intention of giving the baby to them following delivery. It is estimated that every year in the UK, there are between 50 and 70 surrogate pregnancies. The law regarding consent for babies born following such pregnancies is complex: the surrogate mother retains parental responsibility (PR) until a Parental Order or Adoption Order has been confirmed (after 6 weeks old), but other individuals may have capacity to consent in specific circumstances.

**Methodology:**

We surveyed 46 Paediatric consultants, registrars and ANNPs, to investigate their knowledge regarding consent for these babies. We posed a clinical scenario, in which a 2 week old baby required a lumbar puncture as part of a septic screen, and asked who could give consent in different circumstances.

**Results:**

Only 22% of all 46 respondents were able to correctly identify the individuals who could give consent in all five scenarios. 43% respondents knew that the surrogate mother had PR in all scenarios; however 13% incorrectly assumed that either IP always had PR. 43% were aware that the surrogate mother's spouse had PR if they were married or in a civil partnership; 76% knew that if one of the IPs was a sperm donor and named as the father on the birth certificate he could consent; and 80% knew that if there was a Surrogacy Agreement, the IPs could consent.

**Summary:**

Our survey has revealed poor understanding regarding consent for babies born following surrogate pregnancies. Although this situation is relatively uncommon, it may cause a conundrum for healthcare professionals, especially out of hours. Most of the literature regarding guidance in surrogate pregnancies focuses on the antenatal period from an obstetric perspective, and there is a lack of guidance regarding the management of babies after birth. We suggest that specific postnatal guidelines for primary and secondary care should be provided.

Practical suggestions when managing these complex scenarios include: formal but sensitive exploration of who holds parental responsibility, seeking advice from legal services and social care if required; invitations to all involved parties to contribute to management decisions; and formal documentation of consent. Even once the person holding ultimate parental responsibility is identified, the views of all parents should be valued and considered.

Submission by:

Name: DR SONAL DATIR

email: sonal.datir@nhs.net

Institution: STOKE MANDEVILLE HOSPITAL, BUCKINGHAMSHIRE

Mobile: 07884615694

Specialty & Year: PAEDIATRICS, ST4

Wessex Trainee: No

Contact Address: 48, FOSKETT WAY, AYLESBURY. POSTCODE: HP21 9AX

Submission for: Both (POSTER AND PODIUM)

Title: ETHICAL CHALLENGES IN DIAGNOSIS AND COUNSELLING IN A CASE OF BRAIN ANOMALY

Author(s): Dr Sonal Datir, Dr Vineela Mandava

## CASE HISTORY

A 40-year-old pregnant lady with normal anomaly scan at 20 weeks was noted to have severe ventriculomegaly at 27week scan monitored for maternal Polycystic Kidney disease (ADPKD). A foetal MRI at 29 weeks reported gross ventriculomegaly with small dysmorphic cerebellum and compressed brainstem; which raised a possibility of brain maturation disorder like lissencephaly. Microarray and infection screen were negative. Antenatal counselling was provided with poor neonatal outcome irrespective of the cause. Risk of immediate neonatal cardiorespiratory problems and significant postnatal disability was explained.

Given the complexity of situation, parents opted for reorientation of care and not for active resuscitation, expecting a very poor outcome.

The baby girl was born in good condition at 35+4 weeks weighing 2.7kg after a caesarean section. Examination was normal with good tone and activity, normal reflexes; spontaneously breathing and feeding well. Postnatal MRI showed severe hydrocephalus with lissencephaly of the parietal, temporal and occipital lobes with associated thinning of cortex, corpus callosum and cerebellum; but a normal brain stem.

Parental anxiety was remarkably high with significant dilemma due to the unexpected survival. They were explained of a guarded prognosis and discharged home.

## ETHICAL CONUNDRUM

Antenatal counselling was extremely difficult due to uncertain aetiology for the brain appearances. Prenatal diagnosis of an affected foetus allows appropriate counselling and optimization of obstetric management. In our situation, whether this was genetic lissencephaly or an antenatal event is questioned. In the presence of severe ventriculomegaly, evaluation of cerebral sulci with foetal MRI is evidenced to provide better counselling but was unsuccessful to aid in our situation. The presence of brainstem involvement on antenatal imaging posed a risk and therefore a poor prognosis was explained. However, postnatal MRI showed normal brainstem. Literature review did not show any association of ADPKD with ventriculomegaly in foetus. Antenatal counselling regarding the bleak prognosis was questioned and subsequent medical opinions were sought regarding expectations and outcomes.

Counselling parents both antenatally and postnatally is challenging in cases of antenatal ventriculomegaly and brain maturation disorders especially due to uncertain aetiologies and highly variable outcomes in terms of risks to the baby and degree of resulting disability involving regular review of the advanced care plan.

OUTCOME: The baby was discharged with an advanced care plan and follow up by neonatal community nurses along with hospice support for care at home; ophthalmology and audiology referrals were made along with an outpatient follow up and open door access.

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Please read rules for abstract below*

**Submission by:**

Name: Sunitha Vimalasvaran

email: [sunitha.varan@hotmail.com](mailto:sunitha.varan@hotmail.com)

Institution: NICU, Luton & Dunstable Hospital

Mobile: 07537931931

Specialty & Year: Paediatrics ST4

Wessex Trainee: ~~Yes~~ / No

Contact Address: Flat 29, Cambium House, Palace Arts Way, Wembley Park, London HA9 0GH

**Submission for:** ~~Podium~~ / ~~Poster~~ / Both (delete as appropriate)

**Title:** Shared decision-making in the NICU: Is it always appropriate?

**Author(s):** Sunitha Vimalasvaran, Jean Egyepong, Carly Reynolds

**Abstract:**

*(Please consider case history, ethical conundrum, outcome for the cases)*

### **Introduction**

The gangliosidoses are lysosomal storage disorders caused by accumulation of GM1 or GM2 gangliosides, with a continuum of clinical presentations from severe infantile forms to milder adult forms (1). With no cure, supportive medical management may increase lifespan.

### **Case History**

Baby Z was born at 25+5 weeks via caesarean section, following spontaneous onset of labour. With a family history of GM1 gangliosidosis (sibling death at 2 years), Baby Z underwent genetic testing for GLB1 and CTSA- confirming his diagnosis.

He was mechanically ventilated at birth for respiratory distress syndrome. He had multiple failed extubations secondary to seizures, apnoea and poor respiratory effort.

On Day 29 of life, he developed necrotising enterocolitis requiring bowel resection and stoma formation. Subsequent enteral feed intolerance led to a contrast study, which revealed proximal jejunal obstruction. Following another failed extubation, palliative care was instituted to avoid further surgical intervention.

Baby Z was eventually extubated on Day 94 of life and remained on low-flow oxygen. Ongoing TPN-dependence was the stumbling block in preparing his discharge home. Multiple multi-disciplinary and family discussions regarding surgery were held to facilitate enteral feeding alongside palliative care. Differing professional and parental opinions led to complex ethical issues.

### **Ethical conundrum**

Recent studies have advocated shared decision-making as opposed to pure medical autonomy to improve parental participation (2). Doctors play an important role as choice architects in counselling parents in the NICU (3). The discussions with Baby Z's parents were to help them understand his clinical situation and life-limiting poor prognosis, but also to appreciate the meaning of the choices they faced i.e. risks of surgical correction vs. TPN-dependence with associated TPN-hepatitis and infection risk vs. no nutrition at all. Although they did not want him to suffer, they struggled to come to terms with de-escalating treatment and the prospect of losing another child.

### **Outcome**

Parental empowerment (especially in ethical grey zones) is becoming increasingly relevant, as medical advances change perceptions on quality and quantity of life-limiting conditions. As clinicians, we continue our roles to do no harm and work in the best interest of our patients (4), but have the added responsibility of helping parents understand their choices and decisions.

Baby Z was referred to a surgical centre for possible reversal of bowel obstruction to reattempt enteral feeding. After much professional deliberation and parental discretion, this was felt to be in his best interest for the duration of his remaining life.

*(400 words)*

### **References**

1. Regier DS, Proia RL, D'Azzo A, Tiftt CJ. The GM1 and GM2 Gangliosidoses: Natural History and Progress toward Therapy. *Pediatr Endocrinol Rev.* 2016;13 Suppl 1:663-73.
2. Lantos JD. Ethical Problems in Decision Making in the Neonatal ICU. *N Engl J Med.* 2018;379(19):1851-60.
3. Daboval T, Shidler S, Thomas D. Shared Decision Making at the Limit of Viability: A Blueprint for Physician Action. *PLoS One.* 2016;11(11):e0166151.
4. Kopelman LM. Disputes over moral standards guiding treatments for imperiled infants. *Semin Perinatol.* 2009;33(6):372-6

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*F*

**Submission by:**

Name: *Tanja Pedersen*

Email: [tanja\\_pedersen@hotmail.com](mailto:tanja_pedersen@hotmail.com)

[Tanja.Pedersen@helse-bergen.no](mailto:Tanja.Pedersen@helse-bergen.no)

Mobile: +47 4007 4547

Institution: *Haukeland University Hospital, Bergen, Norway.*

Specialty & Year: *Pediatrics 2009*

Wessex trainee: *No*

Contact Address: *Moellendalsveien 68 A, no. 206, 5009 Bergen, Norway.*

**Submission for: *Both***

**Title:** *Organized Pediatric and Neonatal Palliative Care in Scandinavia – why does it take so long?*

**Author:** *Tanja Pedersen, consultant neonatologist*

Since Palliative Care Medicine was acknowledged as a medical subspecialty in the 1960ies colleagues around the world have worked on implementing Palliative Care Medicine in Pediatrics.

In Britain the first private hospice for children opened in the 1970ies and the first in house Palliative Care Department in the 1980ies.

In Scandinavia Palliative Care Medicine was acknowledged in Norway in 2011 as a subspecialty, but since 2003 there has been a common Scandinavian program educating doctors in Palliative Care Medicine.

In Pediatrics we have not come that far. In Norway, the government decided in 2016 that all regional hospitals (level 3 NICU's) should start a Pediatric Palliative Care team that also should guide and assist all other Pediatric Departments in local hospitals. But it was not until April 2019 that one of the five university hospitals managed to fill the request.

In Norway Pediatric Palliative Care is offered by the staff responsible for treating the child – but it is totally dependable on the staff involved, and the quality changing from case to case and hospital to hospital since there are only a few national guidelines. Every decision is up to the responsible neonatologist/pediatrician involved.

How come when it comes to medicine three otherwise updated countries in Scandinavia are lacking that much, when it comes to Pediatric Palliative Care?

Why don't we educate pediatricians in palliative Care?

Lack of resources and economy?

Resistance among staff due to old-fashioned care principles?

The neonatologists and pediatricians thinking, they can manage it all?

Why haven't staff recognized children's and parents / family members need for spiritual, psychiatric, physical and social support from experts?

How can we move forward?



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**Submission by:**

Name: Thomas Hixson  
Institution: Luton and Dunstable  
Specialty & Year: Paediatrics ST3

Email: [thixson@doctors.org.uk](mailto:thixson@doctors.org.uk)

Mobile: 07972123199

Wessex Trainee: No

Contact Address: Neonatal Intensive Care Unit, Luton and Dunstable University Hospital, Lewsey Road, Luton, LU4 0DZ.

**Submission for:** Both

**Title:** Supporting parents; how long is too long to carry on?

**Author(s):** Dr Thomas Hixson, Dr Doris Wari-Pepple.

**Abstract:**

This sad case is centred on a term baby boy who suffered a catastrophic perinatal hypoxic event resulting in severe hypoxic ischaemic encephalopathy (HIE) and eventual death.

The background is of a low risk pregnancy, booked for delivery in a midwife led birthing unit at a district general hospital. On routine observation during labour no fetal heart rate was identified so baby was delivered by emergency caesarean section. He was born through thick meconium liquor with no heart rate, but following extensive cardio-pulmonary resuscitation, including adrenaline, a heartbeat was picked up at fourteen minutes of age. Following transfer to the neonatal unit he had abnormal neurology and developed clinical seizures; therapeutic hypothermia was started and he was transferred to our tertiary level neonatal unit. On arrival he showed evidence of multi-organ dysfunction including an encephalopathy, coagulopathy, renal and liver dysfunction, and a severe metabolic acidosis. After 24 hours of life a thorough neurological assessment was done, showing fixed and dilated pupils, with no brainstem reflexes; the sad news of severe HIE, brainstem death and the poor prognosis was broken to his parents.

It was of the medical opinion early on that continuing cooling therapy and intensive care was not in the patient's best interest. This was conveyed to the parents repeatedly and gently but they refused to accept and engage with the medical team, insisting that full intensive care be continued. This was particularly distressing for the medical staff as it was evident from repeated neurological assessment that there were no signs of brain activity. Our ethical dilemma explores whether prolonging intensive care was acting in the baby's best interest. Was it cruel to carry on in spite of evidence of brain death? Whose interest do the medical team prioritise? The mother repeatedly said she "wants more time with him", which begs us to consider which decision would cause the most harm and who should get priority; the grieving parents or the dying patient. How long is too long to act in the best interest of the patient? How do we support medical staff working in this challenging situation?

After sixteen days of discussions with parents, when it was evident that there was no improvement, they came to terms and agreed for redirection of care. The baby was transferred to the hospice where he passed away surrounded by family, according to his parents' wishes.

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***All abstracts presented will be published on the WONEP website, conference booklet and receive certificates.***

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

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**Submission by:**

Name: Dr Trisha Prentice

email: trisha.prentice@rch.org.au

Institution: Royal Children's Hospital, Melbourne

Mobile: +61 407879229

Specialty & Year: Neonatology

Wessex Trainee: No

Contact Address: 50 Flemington Rd, Parkville, VIC, AUS 3015

**Submission for:** Podium / Both

**Title:** Learning from clinician experiences to address moral distress

**Author(s):** Trisha M Prentice<sup>1,2,3,4</sup>, Dilini Imbulana<sup>2</sup>, Lynn Gillam<sup>4,5</sup>, Peter G Davis<sup>2,6</sup>, Annie Janvier<sup>7</sup>

<sup>1</sup> Neonatal Medicine, Royal Children's Hospital, Melbourne, Victoria, Australia

<sup>2</sup> Newborn Research, Royal Women's Hospital, Melbourne, Victoria, Australia

<sup>3</sup> Murdoch Children's Research Institute, Melbourne, Victoria, Australia<sup>[1]</sup>

<sup>4</sup> Melbourne School of Population and Global Health, University of Melbourne, Melbourne, Victoria, Australia

<sup>5</sup> Children's Bioethics Centre, Royal Children's Hospital, Melbourne, Victoria, Australia

<sup>6</sup> Department of Obstetrics and Gynaecology, University of Melbourne, Melbourne, Victoria, Australia

<sup>7</sup> Department of Pediatrics, Division of Neonatology, Clinical Ethics Unit, Palliative Care Unit, Unité de Recherche en Éthique Clinique et Partenariat Famille, CHU Ste-Justine, Montreal, Quebec, Canada

**Abstract:****Background:**

The negative impacts of moral distress on clinicians are now well recognised within acute care settings. Interventions to reduce clinician burnout, enhance job satisfaction and protect clinician moral integrity are sought. We aimed to evaluate the impact of participation in a longitudinal, non-interventional research project on moral distress within two NICUs in Australia to give insights into considerations for interventional studies on moral distress.

**Methods:**

All medical and nursing providers who participated in research on moral distress in two NICUs in Melbourne, Australia were invited to complete a questionnaire on the impact of participation. The original study (MoDaLiTy: Moral Distress and Life Trajectories) required regular completion of surveys that sought predictions of death, disability and the intensity of moral distress experienced in caregivers of babies born <28 weeks. Preferred level of intervention by the clinicians and perceived parental wishes were recorded. In this study, individual and unit-wide effects of participation were explored. Open-ended questions were analysed using qualitative methodology.

**Results:**

A total of 249/463 (53%) eligible healthcare providers participated. Participation in MoDaLiTy was perceived as having a positive impact by 58% of participants. Providers found articulating their views therapeutic (77%) and at least sometimes useful in clarifying personal opinions about the babies (85%). Qualitative responses revealed the research stimulated increased reflection, validated feelings and increased dialogue amongst healthcare providers. However, a small number of medical providers felt the focus of discussion unhelpfully shifted from the baby to the providers, impacting shared decision-making and potentially care provision.

**Conclusions:**

Research into moral distress can be useful in clarifying personal views that may influence the care of neonates. While increased discussion regarding moral distress may not reduce its prevalence, it can facilitate better communication around difficult clinical scenarios and improve satisfaction.

Reflecting on clinician experiences of participating in research on moral distress, this paper will suggest considerations and potential outcome measures for interventional studies on moral distress to enable more robust research that considers the multitude of stakeholders that are impacted by the experience of moral distress.

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Submission indicates consent for possible publication of this material on the WONEP website and the conference booklet. Please return as a word document by email to [mproveonline@gmail.com](mailto:mproveonline@gmail.com)  
Please read rules for abstract below*

**Submission by:**Name: **Prof Maria Brenner**email: **brennerm@tcd.ie**Institution: **Trinity College Dublin**

Mobile:

Specialty &amp; Year:

Wessex Trainee: Yes / No **NO**Contact Address: **School of Nursing & Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2, D02 T283, Ireland,****Submission for: / Poster /** (delete as appropriate)**Title: Evolving influences on the initiation of life-sustaining technology in children****Author(s): Dr Denise Alexander, Jessica Eustace-Cook, Prof Maria Brenner****Abstract:***(Please consider Background/Method/Results/Conclusions/Key/Messages for studies)**(Please consider case history, ethical conundrum, outcome for the cases)*

**Background:** The emergence of sophisticated life-sustaining medical technology in paediatrics has saved thousands of lives, however, little is understood about the dynamic circumstances within which the initiation of technology dependence takes place. The central purpose of the ERC-Funded TechChild project is to investigate the influences (conscious and unconscious) surrounding the initiation of technology dependence when a child is critically ill. This aim of review was to identify how decisions were made in the past, and what current issues require further exploration and consideration.

**Methods:** Using broad search terms to describe key concepts, such as technology dependence, physical disability, chronic illness and complex care needs of children, we identified 1133 scientific papers ranging from the 1970s to the present day. A three-stage process of title and abstract screening, initial full-text scanning, and in-depth full text reading resulted in 178 relevant papers. Although relatively few papers specifically focused on the initiation of technology dependence in children, relevant discussions were identified around decision-making in intensive care, and the withdrawing or withholding treatment at the end of life.

**Results:** We identified three inter-related broad themes: the ability of life-sustaining technology to alter the meaning of futile care; dissonance in perspectives of decision-making; and the emergence of joint-decision making. Changes within these themes describe the evolution of the complex and challenging ethical debates about the initiation or non-initiation of life sustaining technology. Changes in approaches to the use of life-sustaining technology by physicians; society's attitudes to technology; and the increasing influence of wider perspectives on decisions, such as child well-being, were described by the literature. The fundamental philosophies of 'preserving life at all costs' or 'do no harm' have been challenged as insufficient to guide ethical practice; the role of physicians as lone, impartial decision makers, and the role of parents from passive observers has changed as the need for collaborative decision processes becomes apparent to navigate the complex and new ethical environment.

**Conclusions:** Decisions about the initiation or not of life-sustaining technology has created ethical challenges that have changed the traditional role of medicine, of physicians and of parents. Attempts to find decision-making consensus in the context of challenging ethical debates and very different viewpoints are difficult.

**Key messages:** There remains a lack of evidence about the current overt and implicit influences on decision-makers surrounding the initiation of technology dependence. Understanding these will lead to greater clarity in decision-making in this context.

## ABSTRACTS FOR EUROPEAN NEONATAL ETHICS CONFERENCE

We invite abstracts for the European Neonatal Ethics Conference to be held at St Mary's Stadium

Abstracts not more than 400 words should be submitted to [mproveonline@gmail.com](mailto:mproveonline@gmail.com) no later than the 15<sup>th</sup> of July 2019.

Abstracts can consist of the following

1. Work focussing on neonatal ethical conundrum
2. Interesting cases which allow for panel discussion amongst the delegates
3. Epidemiological studies/data raising interesting ethical questions
4. Research in the field of ethics with implications for neonatal care

Podium/Poster Presentations-There will be podium presentations at the conference to be held on the 15<sup>th</sup> of November 2019. There will also be place for posters to be presented at the poster walk session.

Abstract submission deadline 15<sup>th</sup> June 2019

Notification of podium/poster 30<sup>th</sup> June 2019

*Note the presenting author will need to register for the main conference and this will be at the discounted rate.*

***There will be an award for the Young Investigator, Best oral presentation and Runner up.***

***There will also be a poster award.***

***All abstracts presented will be published on the WONEP website, conference booklet and receive certificates.***

# European Neonatal Ethics Conference

## Oral or Poster: Abstract Submission

**Submission by:**

Name: Martins Aso

Institution: Princess Anne Hospital

Specialty & Year: Neonates

Contact Address: Neonatal Unit, Princess Anne Hospital, Southampton

email: drmartinsaso@yahoo.com

Mobile: 07725713005

Wessex Trainee: No

**Submission for:** Podium

**Title:** Resuscitation of Preterm Infants in Nigeria: A national survey on practice.

**Author(s):** Martins Elo Aso, Alok Sharma, Kenechukwu Kosisochukwu Iloh

**Abstract:****Background and Aims**

Preterm births constitute a major clinical problem associated with significant morbidity and mortality in the perinatal, neonatal and childhood periods. Majority of preterm births occur in low-income and middle-income countries where there are no published guidelines which guide clinicians resuscitating preterm infants (PIs) in these settings. Nigeria being the most populous country in Africa has the third highest number of preterm births worldwide. This study aims to assess the practice and decision making that surrounds the resuscitation for PIs by neonatologists and neonatal nurses working in neonatal intensive care units (NICUs) across Nigeria.

**Methods**

We conducted a national survey on neonatal care providers across NICUs in Nigeria. Participants were selected from the six geopolitical regions of Nigeria. Respondents were asked about current practices relating to resuscitation and estimated survival rates of PIs of different gestational ages. We also requested information on factors influencing the clinician's decision to offer or withhold resuscitation of PIs.

**Results**

In total, 86 clinicians responded to our survey. Of this, 47 completed the survey (response rate 55%). Majority of the responses were submitted by neonatologists (77.4%). Approximately two-thirds of the responses were from Teaching hospitals while the remaining was from Specialist (26.3%), Central (6.3%) and General Hospitals (2.5%). Three quarters of respondents report having a guideline for resuscitating the preterm infant. There is a considerable variation in resuscitation practices however majority of healthcare providers initiate resuscitation from a GA of 26 weeks but in cases where the GA is uncertain a birth weight of  $\geq 500$ g is used as the threshold for providing active treatment (28%). Survival rates for PIs were higher in Teaching hospitals than in Central/General

hospitals. The major factor influencing a clinician's decision to offer or withdraw care is the quality of life of the PIs. Thirty nine percent of clinicians agreed to have withdrawn care and palliate the PIs and majority of respondents reported that the infant remained intubated but did not provide further treatment.

#### Conclusion

Our survey revealed considerable variation in resuscitation practices by different neonatologists and neonatal nurses. A developed and published national guideline that is used by all NICUs may generate greater consistency of care. Providing support for families and hospital staff involved in palliative care of these PIs will help in overcoming some of the challenges faced these parents and staff.