

European Neonatal Ethics Conference – 2019

“Sharing Ethical Practice Together”



This event has been endorsed by ESPNIC (European Society of Paediatric and Neonatal Intensive Care)

RCPCH CPD have been applied for

Venue St Mary's Stadium, Britannia Road, Southampton United Kingdom

Date 14th and 15th of November 2019



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

Professor Anneke Lucassen

Professor of Clinical Genetics, Faculty of Medicine, University of Southampton

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: @Neonatalethics

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

0800-0900

REGISTRATION (Foyer)

Tea & Coffee Marcus Liebherr Lounge



0900-1100

MAIN CONFERENCE -MIKE CHANNON SUITE



SESSION 1 COMMUNICATION

Chair-Karen Brombley

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 Marcus Liebherr Lounge



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 Shannon 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



Terry Paine 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 Marcus Liebherr Lounge *Please note this will be a fork buffet

Poster Walk and Short Oral Presentations

1300-1415 **SESSION 3 PALLIATIVE CARE (3 Themes Participants Attend 1 workshop)**



Matt Le Tissier Suite



Mike Shannon Suite



Terry Paine 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.

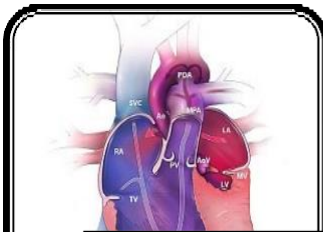
International Perspectives

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

1415-1515 **SESSION 4 HOT TOPICS ROUND TABLE CASE PRESENTATIONS**



Matt Le Tessier Suite

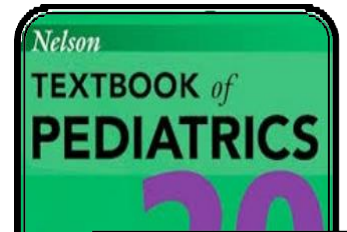
"Variation of practice in counselling and interventions for hypoplastic left heart syndrome: what is acceptable?"

Keith Barrington



Mike Shannon Suite

Abstracts



Terry Paine Suite

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

Annie Janvier

Abstract Presentations Mike Shannon Suite Chair Jasim Shihab and Karen Brombley

*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***

1515-1545 Tea & Coffee Marcus Liebherr Lounge

1545-1730 **Session 5 Plenary Sessions**

1545-1645 **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**

1645-1730 **Plenary 2**

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

Chair-**Dr Alok Sharma**

Speaker- **Professor Hugo Lagercrantz**

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Day 2

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SESSION 6 ETHICAL DILEMMAS IN NEONATAL CARE

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 I 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 Marcus Liebherr Lounge



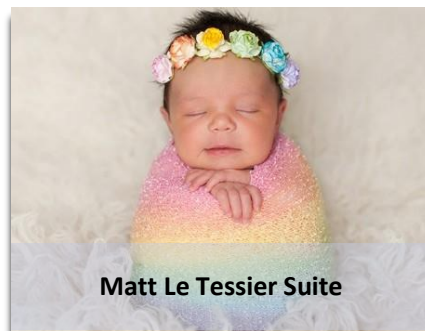
1130-1230 **SESSION 7 PARENTS PERSPECTIVE & *Abstracts**

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



Mike Shannon Suite

Neonatal Palliative Care
Abstracts 1-4 15 minutes each



Matt Le Tessier Suite

Rainbows and Storm clouds
How do parents cope with neonatal loss. How do they support others in the same position?



Terry Paine Suite

Ethical Issues at Limits of Viability
Abstracts 4-8 15 minutes each

Abstracts

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* **Dr Beatrice Lechner, Providence, USA**
5. *The collective burden of perinatal care in the 22nd week of gestation: Is the focus of contemporary ethical controversy misplaced?* **Dr Naomi Laventhal, 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 8 PLENARY-GENOMICS

'Genomics-The Holy Grail'

Anneke Lucassen

1410-1450

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

Felicity Boardman

1450-1600

SESSION 9 SCIENTIFIC SESSIONS



Matt Le Tissier Suite



Mike Shannon Suite



Terry Paine 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

- 1. End of life decisions and Ethical Issues in the NICU-Physician attitudes and self-reported practices in Greece** **Dr I Chatzioannidis, Athens, Greece**
- 2. Best interests of the child in the age of social media** **Dr Emma Nottingham, Winchester, UK**
- 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**

1600-1630

Coffee

1630-1730

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.

I have 2

Expensive treatments and Healthcare Rationing

How should be we managing parental expectations in publicly funded healthcare systems?

Are ethical considerations and principles as applied in developed countries applicable to parents from different countries,

Who has to live with the consequences?