

# 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-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 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 Shannon 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.

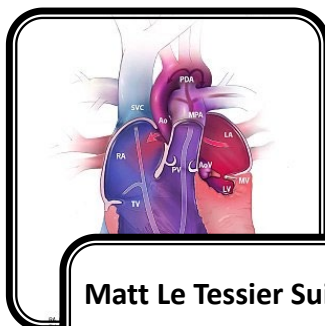
**International Perspectives**

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**

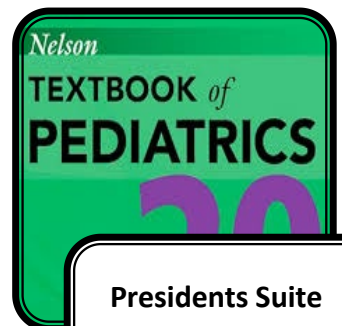
"Variation of practice in counselling and interventions for hypoplastic left heart syndrome: what is acceptable?"

**Keith Barrington**



**Mike Channon Suite**

**Abstracts**



**Presidents Suite**

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

**Annie Janvier**

*Abstract Presentations Mike Channon 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***

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 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 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**



**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**



**Ethical Issues Limits of Viability**

**Abstracts 4-8 15 minutes each**

**Chair Karen Brombley 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* **Dr Beatrice 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 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 7b PARENTS PERSPECTIVE

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



**Mike Channon Suite**



**Matt Le Tessier Suite**



**President 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. 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**



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.