European Neonatal Ethics Conference – 2019
“Sharing Ethical Practice Together”

November 14th and 15th 2019

Venue:
St Mary’s Stadium, Britannia Road, Southampton, SO14 5FP

SPEAKERS

Professor Keith Barrington
Professor of Paedics, University of Montreal, Quebec Canada

Professor Howard Clark
Professor and Head Academic Child Health UHS Southampton

Dr Rosa Geurtzen
Fellow in Neonatology and Neonatal Research, Radboud University, Amalia Children’s Hospital, Netherlands

Dr Annie Janvier
Associate Professor Department of Paedics Consultant Neonatologist & Ethicist, University of Montreal, Quebec, Canada

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

Professor Neil Marlow
Professor of Pediatrics, UCL, President European Society of Pediatric Research

Dr Sofia Moratti
Max Weber Postdoctoral Fellow, European University Institute, Florence

Dr Trisha Prentice Newborn Research
Royal Women’s Hospital Melbourne Australia

Mr Rob 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 Woolard
Chair Faculty Ethics Committee UHS Southampton
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 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.
Programme

0800-0900  Registration (Foyer)

0900-1100  **SESSION 1 COMMUNICATION**

**Chair-Dominic Wilkinson**

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 baby’s
            What research tells us?
            Neil Marlow

1000-1030  Integrating parental voices in Neonatology
            Annie Janvier

1030-1100  Tea & Coffee

1100-1200  **SESSION 2 COMMUNICATION IN DIVERSE CIRCUMSTANCES**

1200-1300  Lunch
1300-1415  SESSION 3 PALLIATIVE CARE (3 Themes Participants Attend 1 workshop)

Moral Distress on the NICU  
Trisha Prentice & Lisa Leppard

Palliative Care International Perspectives  
Rosa Guerten & Dominic Wilkinson

Limiting Nutrition in Neonatal Care  
Amy Rushbrook Sijo Francis

1415-1515  SESSION 3 HOT TOPICS Roundtable-

Is it ethical to offer termination to neonates with HLHS  
Keith Barrington

Ethical (Mal) Practice in Research  
Howard Clarke

Managing Trisomy 13/18  
Not what the book said  
Annie Janvier

1515-1545  Tea & Coffee

1545-1645 Resuscitation at Extremes of Viability-Current Evidence & Practice

Chair- Professor Dominic Wilkinson

British Association of Perinatal Medicine Framework- Neil Marlow

Canadian Neonatal Network Guidance- Keith Barrington
1645-1730 Making Complex Ethical Decisions in Neonatal Care - Panel Discussion

Chair Lisa Leppard Case Presentation

Mr R Wheeler (Lawyer)

Karen Brombley (Nurse)

Sijo Francis (Consultant Neonatologist)

Dominic Wilkinson (Ethicist)
Programme

0830-0900  Introduction & Recap to the Day
            Chair Dominic Wilkinson

SESSION 1-ETHICAL DILEMMA

0900-0940  Do babies have a right to breastmilk?
            Fiona Woollard

0940-1020  Who decided whether I am a Boy or a Girl?
            Sex and gender ambiguity: Ethical dilemmas in healthcare for infants and children with DSD/intersex
            Claudia Wiesmann

1020-1100  “Impossible Decisions in Neonatal Care”
            Robert Wheeler

1100-1130  Tea & Coffee

1130-1230  SESSION 2-ETHICAL POTPOURRI

Abstracts Session 1
Cases
Rainbow’s & Stormclouds
Bereaved Parents & Subsequent Pregnancy

Abstracts Session 2
Spectrum of Palliative Care
1230-1330  Lunch

1330-1410  Session 3 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

1500-1600  Session 4  AFTERCARE

1600-1630  Coffee

1630-1730  The NICU Parent Panel-
Anything You Wanted to Ask an NICU Parent?
Annie; Keith; Ali; Peter