

European Neonatal Ethics Conference – 2016

“Sharing Ethical Practice Together”

June 2nd 2016

Venue:

Kassam Stadium Grenoble Road

Oxford

OX4 4XP



Speakers

Professor Margot Brazier

Professor, School of Law, The University of Manchester, Chair: Nuffield Council on Bioethics Working Party The Ethics of Prolonging Life in Fetuses and the Newborn 2004-2006.

Dr Joe Brierley

Consultant in Paediatric Intensive Care and Ethics, Great Ormond Street Hospital for Children, Co-Chair GOSH Clinical Ethics Committee & Medical President of ESPNIC

Dr Mirjam De Vos

Senior Advisor at Council for Public Health and Care, Academic Medical Centre, Amsterdam Netherlands

Dr Mike Hall

Consultant Paediatrician & Neonatologist, University Hospital Southampton; Hon. Senior Clinical Lecturer in Child Health, University of Southampton

Dr Brenda Kelly

Consultant Obstetrician & Fetal Medicine, John Radcliffe Hospital, Oxford

Professor Ingrid Miljeteig

Associate Professor in Medical Ethics, University of Bergen, Bergen, Norway

Professor Neil Marlow

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

Dr Sofia Moratti

Research Fellow, European University Institute, Florence

Professor Dominic Wilkinson

Director of Medical Ethics at the Oxford Uehiro Centre for Practical Ethics, University of Oxford; Consultant Neonatologist, John Radcliffe Hospital, Oxford

Professor John Wyatt

Emeritus Professor of Ethics at University College London and Retired Consultant Neonatologist University College Hospital

Professor Dominic Wilkinson, Chair & Lead European Neonatal Ethics Conference



Dominic Wilkinson is the Chair and Lead for the European Neonatal Ethics Conference. He is Associate Professor and Director of Medical Ethics at the Oxford Uehiro Centre for Practical Ethics, University of Oxford. He is also a consultant neonatologist at the John Radcliffe Hospital, Oxford. Dominic trained in neonatal intensive care in Melbourne and has also worked as a doctor in adult and paediatric intensive care units. He completed a Masters degree in Human Bioethics in Australia and a DPhil in Bioethics in Oxford on the ethical implications of magnetic resonance imaging in newborn infants with birth asphyxia. Dominic has written a large number of academic articles relating to ethical issues in intensive care. He is the author of a critically-acclaimed book "Death or Disability? The 'Carmentis Machine' and decision-making for critically ill children" Oxford University Press 2013. He is Associate Editor of the Journal of Medical Ethics and Managing Editor of the Journal of Practical Ethics. He is also co-author of an online handbook-"Caring-decisions".

Link-www.rch.org.au/caringdecisions.

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 and Neonatal Simulation Programme at Princess Anne Hospital Southampton. 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, Portsmouth 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.

Dr Mike Hall Co-Organizer & Chairman of Abstracts



Dr Mike Hall is a consultant neonatologist at the Princess Anne Hospital, Southampton. He has an interest in undergraduate and postgraduate education in paediatric and neonatal medicine, including teaching on ethical issues. He is the medical coordinator of the University of Southampton MSc course designed for the development of advanced neonatal nurse practitioners and he is the Director of the NOTE international online postgraduate neonatology education programme. Dr Hall is Visiting Professor at the Centre for Innovation and Leadership within the Faculty of Health Sciences at the University of Southampton.

Professor Margot Brazier



Margaret Brazier has taught at Manchester University since 1971. She became Professor of Law (1990) and was Director of the University's Centre for Social Ethics and Policy until 2010. She has undertaken a range of research projects, including EU funded research into the ethics of control of communicable diseases and reproductive choice. She was the principal investigator on an AHRC funded project 'The Impact of the Criminal Process on Health Care Practice and Ethics'. She has written widely on medical law and ethics, with an interest in problems of autonomy & consent, the use of human body parts, reproductive medicine, and medico-legal history. From 1996-1998 she chaired a review into surrogacy laws. From 2001-2004 she chaired the Retained Organs Commission, and from 2004 -2006 she chaired a Nuffield working group on critical care decisions in fetal and neonatal medicine. She is a Fellow of the British Academy and the Academy of Medical Sciences and was appointed QC (*honoris causa*) in 2008. She will be involved in both the workshops and conference sharing her wealth of experience with everyone attending the conference.

Dr Joe Brierley



Dr Joe Brierley is a Consultant Paediatric Intensivist at Great Ormond St Hospital for Children in London. He is also Vice-Chair of the Paediatric Bioethics Committee at Great Ormond St Hospital for Children, London. He is lead for organ donation at GOSH and has presented widely on this topic.

Joe currently chairs the RCPCH Ethics & Law Advisory Committee. He is president of the European Society of Paediatric & Neonatal Intensive Care, & lead for Diploma here. His research interests include septic shock and hemodynamics, medical ethics, end of life care and ICU and organ donation in childhood.

Disorientated London (errrr...not) Wasps Rugby supporter.....

Dr Mirjam De Vos



Mirjam de Vos-Broerse (1960) is a researcher in the field of medical communication and medical ethics. She works in the Academic Medical Center (AMC) of Amsterdam. She combines her research with working as an ethical consultant and as a trainer in communication skills for the Department of Paediatrics. Besides her work in the AMC, she is senior consultant for the Dutch Centre of Consultancy and Expertise (CCE). When the quality of life of children and adults in need of long-term care becomes seriously compromised, they or their caregivers can apply to the CCE for exceptional care and mediation.

Mirjam is married and has three children. Her eldest daughter Rebecca, now 24 years old, suffers from Angelman Syndrome. She lives partly at home and partly in a small care home.

Dr Brenda Kelly



Dr Brenda Kelly is a Consultant Obstetrician and Subspecialist in Fetal Medicine at Oxford University NHS Hospital Trust. She is also director of the Oxford Rose Clinic, a specialist clinic for women and children with female genital mutilation. Dr Kelly undertook core training in London and Oxford and was appointed as a consultant in Oxford in 2012. Her current research interests include prenatal screening for aneuploidy and patient experience of diagnosis and care pathways around fetal growth restriction. Dr Kelly, a medical graduate from University of Edinburgh, completed her PhD in 2003. Her doctoral research elucidated the role of matrix metalloproteinases in vascular adaptation in pregnancy. This work was supervised by Professor Lucilla Poston and funded by a BHF Clinical PhD studentship. In addition to her research into maternal cardiovascular health, Dr Kelly has completed subspecialist training in Maternal and Fetal Medicine.

Professor Ingrid Miljeteig



Ingrid Miljeteig (MD, PhD) is an associate professor in medical ethics at the University of Bergen, Norway and she is part of the research group Global Health Priorities. She also works as a special adviser in ethics at the Haukeland university hospital in Bergen, Norway. Her research has primarily been on clinical ethical dilemmas experienced in low income countries, especially focusing on ethical dilemmas concerning treatment of sick and premature newborns and on priority setting dilemmas. Previously she has conducted several fieldworks in Indian neonatal units, and at the time several studies on ethical dilemmas and catastrophic health expenditures are ongoing in Ethiopia.

Professor Neil Marlow



Neil Marlow is Professor of Neonatal Medicine at University College London and current Chair of the NHS England Neonatal Critical Care Clinical Reference Group. He took up this appointment following 11 years as Professor of Neonatal Medicine at Nottingham and 7 years as Senior Lecturer in Bristol. He is an Honorary Consultant in the University College Hospital Neonatal Service. His major academic interests have been in long-term outcomes following prematurity. He is the Director of the MRC-funded EPICure studies (www.epicure.ac.uk). He runs a series of local studies into brain and cognitive development following very preterm birth and is a co-investigator on a range of mainly UK based cohort and randomised studies. Neil has been President of the British Association for Perinatal Medicine, Director of the UCL Institute for Women's Health, President of the European Society for Paediatric Research and Chair of two European Academy of Paediatric Societies Meetings. He was elected a Fellow of the Academy of Medical Sciences and is an Honorary Life Friend of Bliss, the UK-based charity for premature babies. He has recently been appointed to the executive of the European Foundation for the Care of Newborn Infants.

Dr Sofia Moratti



Dr Sofia Moratti is a Research Fellow at the European University Institute in Florence, Italy. In 2009 she received a Ph. D. in Regulation of Medical Behaviour from the University of Groningen in the Netherlands. Her areas of expertise directly relevant to neonatology include the ethics, regulation and medical practice of End-of-Life Decision-Making in the NICU, in particular the role of the parents, the notion of "quality of life" and the boundaries between non-treatment decisions and deliberate ending of life, all of which she has investigated in a multi-disciplinary, ethical, socio-legal and empirical perspective.

Professor John Wyatt



John Wyatt is Emeritus Professor of Neonatal Paediatrics at UCL. He worked for more than 25 years as an academic neonatologist at a major perinatal centre in London.

His main research work has been in the prevention and treatment of brain injury in newborn babies including the development of hypothermia treatment for asphyxiated newborns. He has a long-standing interest in contemporary ethical debates about advances in medical technology and the beginning and end of life, and has frequently engaged in public and media debates about controversial issues in medical ethics. He is currently leading a multidisciplinary research project into the social, philosophical and religious implications of advances in artificial intelligence and robotics, based at the Faraday Institute, University of Cambridge.

He has written two popular books on ethical topics *Matters of Life and Death* and *Right to Die?*

Helen Roper and Chris Gomez



Chris Gomez and Helen Roper are the parents of Rumer who was born on the 24th September 2015. Rumer was diagnosed with trisomy 18 before birth. Since Rumer's diagnosis, Chris and Helen have been interested in the issues surrounding the care of babies with trisomy 18 in the UK. They blog about Rumer and more general trisomy 18 issues at www.rumersrainbow.co.uk .
Twitter @RumersRainbow

European Neonatal Ethics Conference – 2016

“Sharing Ethical Practices Together”

Session 1: Ethical Considerations Impacting Decisions

- 08.15-09.00 **Registration**
- 09.00-09.05 **Introduction**
- 09.05-09.30 **Resources and futility in intensive care**
Professor Dominic Wilkinson
- 09.30-10.00 **Should parents’ ability to take care of the child be taken into account in decision-making about treatment in the NICU?**
Dr Sofia Moratti
- 10.00-10.30 **Shared decision-making in the NICU and PICU.**
Theory vs practice
Dr Mirjam De Vos
- 10.30-11.00 **Ethical dilemmas in the NICU in developing countries**
Professor Ingrid Miljeteig

11.00 - 11.30

Coffee (Poster Walk)

Session 2: Limits of Viability

Debate-Nuffield and BAPM guidelines around extremely premature infants - are they still valid?

Chair-Professor Margot Brazier

- 11.30 - 11.45 For: Professor Neil Marlow
- 11.45 - 12.00 Against: Professor John Wyatt
- 12.00 - 12.30 Panel Discussion

12.30-13.30

Lunch and POSTER PRESENTATIONS

Session 3: Podium Presentations

- 13.30-15.30 **“Case Presentations”**
Facilitator: Dr Mike Hall

15.30 - 15.50

Tea

Session 4: Controversies and Challenges in Neonatal Ethics

- 16.00-16.30 **Controversies in neonatal organ donation**
Dr Joe Brierley
- 16.30- 17.00 **Ethical challenges in prenatally diagnosed severe congenital malformations**
Dr Brenda Kelly
- 17.00-17.30 **Communication around End of Life decisions**
Prof Neil Marlow
- 17.30-18.00 **Rumer’s Story-A parental perspective**
Chris and Helen

18.30

Prizes, Feedback and Close

Podium Presentation (13.30-15.30)

Title: End-of-Life Decision-Making in Infant Medical Neglect – Who Decides?

Christopher A. Collura, MD, Mayo Clinic Children's Centre, Rochester

Author(s): Megan J. Thorvilson, MD, M Div; Christopher A. Collura, MD

Title: Ethical dilemmas around long-term ventilation in the neonatal period: Is LTV an option?

Lidia Casanueva: Long-term Ventilation. Hospital-to-Home,

Royal Brompton Hospital, Royal Brompton & Harefield NHS Foundation Hospital, London SW3 6NP, UK

Author(s): Lidia Casanueva, Ruth Wakeman, Gaurav Atreja, Joanna Keating, Gillian Halley

Title: Ethical and practical challenges with neonatal organ donation: a case study

Nanditha Nandakumar, Royal Bolton Hospital, Bolton, UK

Authors: Nanditha Nandakumar, Archana Mishra

Title: Consent in dis(array)? Bioethical and clinical considerations in the use of genome wide testing for neonatal patients

Katherine Burke. Institute of Medical Genetics, University Hospital Wales, Cardiff, CF14 4XW

Author: Katherine Burke

Title: HIE and the timing of death after parental involvement

Louise Anthony, Heartland's Hospital Neonatal Unit, Birmingham

Author: Louise Anthony

Title: Priority to the newborn? Exploring norms, perceptions and values surrounding newborn illness and death in Ethiopia

Kristine Husøy Onarheim,

Department of Global Public Health and Primary Care, Kalfarveien 31, N-5018 Bergen, Norway

Author(s): Onarheim, KH, Sisay MM, Gizaw, M, Moland KM, Norheim OF, Miljeteig, I

Poster Presentation (Oral) 13.00-13.30

Title: A Testing Triumvirate - Edwards syndrome, Oesophageal atresia and Cardiac anomalies

Shazia Sharif, Paediatric Surgery, The Royal London Hospital, Whitechapel Road, London UK

Author(s): Shazia Sharif, Ashwini Joshi, Michael Hird

Title: Coroner referral: Variation of neonatal unit death referrals in England and Wales

Rebecca Musson, Jessop Wing, Sheffield, UK

Author: Rebecca Musson

Title: Parental Requests for "Full Treatment" in Trisomy 13 and 18: new ethical challenges

Peter Brooke, Neonatal Intensive Care Unit, Norfolk and Norwich Hospital NHSFT, UK

Author(s): Peter Brooke, Paul Clarke

Title: Separate legal and ethical epochs in extreme prematurity

Melissa Luig, Neonatal Unit, Westmead, New South Wales, Australia

Author: Melissa Luig

Title: Palliation before and after birth: Changing ethical dilemmas of managing the infant with large thoracolumbar myelomeningocele

Sadaf Bhayat, Neonatal Intensive Care unit, Luton and Dunstable University Hospital, U.K.

Author(s): Sadaf Bhayat, Harsha Gowda

Title: Do advances in neonatal management delay ethical decision making?

Carly Reynolds, Neonatal Intensive Care unit, Luton and Dunstable University Hospital, U.K.

Author(s): Carly Reynolds, Jogesh Kapadia, Paramasivam Sivakumar Luton UK

Posters

A. Theme-Managing prenatal and postnatally diagnosed congenital disorders

Title: “When is a termination not a termination? The ethical importance of understanding in perinatal end of life care.”

Author(s): E Bendle, T Hildebrandt, V Balodima, R Hain, Cardiff, UK

Title: Confined placental mosaicism – an unexpected genetic result

Author: Lucy Boucher, Warwickshire, UK

Title: Trisomy 18: Should we resuscitate?

Author(s): Grace Kwok, London, UK

Trisomy 18 – Deferring to Parental Preference

Author(s): Samantha Stiles, Anthony Kaiser, London, UK

Title: Trisomy 18 – to treat or not to treat.

Author: Dr Tanja Pedersen, Bergen, Norway

B. Theme-Case reports highlighting ethical conundrum

Title: A case of “failed partnership”

Author(s): S. Leontiadi, T. Dassios, A. Hickey, London, UK

Title-Difficulties in limiting Nutrition- ‘NG feeding in a neonate with an Encephalocoele’

Author: Nicola Johnson, Taunton, UK

Title: Role of the ethics committee in the leading a difficult decision-making process

Author: Dr Maria Martin, Alicante, Spain

Title: Extensive Retinal Haemorrhages in A Preterm Infant: Diagnostic Dilemma

Author(s): Nazakat Merchant, Sankara Narayanan, Gillian Adams, London, UK

Title: “Against all odds”- a curious case study of baby X

Author(s): Dr Amitava Sur, Dr Claudia Olivera, Dr Susan Albersheim, Vancouver, Canada

C. Theme-Limits of viability

Title: A Practical Approach to Care When the Margins of Viability Diverge and Practice Guidance Conflicts

Author(s): Christine Bishop, North Carolina, USA

Title: The parent's role in taking difficult decisions about their seriously sick child in the NICU

Author(s): Ann-Britt Heinemann Jallo¹, Ylva Thernström Blomqvist, Torbjörn Tännsjö, Ann Edner, Uppasala, Sweden

Title: The Janus face of gestational age based guidelines for life/death decision-making at the borderline of viability

Author(s): André Kidszun, Mainz, Germany

A Difficult Case at the Borderline of Viability

Author(s): Samantha Potter, Richard Thwaites, Portsmouth, UK

Title: Fragile lives with fragile rights: justice for babies born at the limit of viability

Author(s): Manya J. Hendriks, John D. Lantos, Zurich, Switzerland

D. Clinical Trials; Legal Issues; Treatment; Newer Therapies

Title: Prevention or Cure? Umbilical cord blood and the preterm brain; The ethical conundrum of umbilical cord blood sampling and neurodevelopmental sequelae

Authors: Charlotte Lea, Karen Luyt, Bristol, UK

Title: Proxy Consent for Neonatal Clinical Trials: Ethical Problems and Recommendations for Practice

Author: Katherine Wade, Proxy Consent for Neonatal Clinical Trials: Ethical Problems and Recommendations for Practice

Title: Is laser treatment for Retinopathy of Prematurity (ROP) always the right choice?

Authors: J Baker, A Bean, A, S Clarke, Sheffield, UK

Title: Challenges in reorientation of neonatal intensive care to palliative care

Author(s): Sadaf Bhayat, Paramasivam Sivakumar, Harsha Gowda, Luton, UK

Title: Decision-making in neonates with severe congenital single organ impairment

Author(s): Dr. Anushma Sharma, Dr. Michelle Koh, Southampton, UK

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