

# European Neonatal Ethics Conference – 2014

## “Sharing Ethical Practices in Europe”

Friday 2<sup>nd</sup> May 2014

### Venue:

Chilworth Manor Hotel

Southampton

SO16 7PT



### Speakers

#### **Professor Anneke Lucassen**

Professor of Clinical Genetics, University of Southampton & Consultant in Clinical Genetics, University Hospital Southampton

#### **Dr Angela Fenwick**

Senior Lecturer in Medical Ethics & Education, University of Southampton

#### **Dr Dominic Wilkinson**

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

#### **Professor Marina Cuttini MD MPH PhD**

Director, Perinatal Research Unit, Bambino Gesù Children's Hospital, Rome, Italy

#### **Dr Mike Hall**

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

#### **Professor Pieter Sauer**

Professor of Pediatrics, Groningen University

#### **Dr Robert Ironton**

Consultant Paediatrician & Neonatologist, University Hospital Southampton

#### **Mr Robert Wheeler**

Director of Clinical Law & Consultant Paediatric and Neonatal Surgeon, University Hospital Southampton; Hon. Senior Lecturer in Clinical Law, University of Southampton

## FOREWORD

Some years ago, one Saturday afternoon, I found myself, a recently-appointed neonatologist, musing on a discussion which I had just had with the parents of two-day-old, 27-week twin girls, Laura and Beth, both still on ventilators. I had asked for the meeting because I wanted to give the parents an “update”. Central to this was that ultrasound scans had shown that, while that of Laura was reported to be normal, Beth’s showed bilateral intraventricular haemorrhages, with a probable parenchymal haemorrhage on one side and uncertain parenchymal appearances on the other. I had outlined the possible neurodevelopmental implications and inexpertly invited them to consider whether we were “doing the right thing” by Beth in continuing to provide life support. The father was a finance director by profession and his immediate instinct had been to draw up a balance sheet: “positives” on the left and “negatives” on the right. I remember that at the top of the left-hand column he had carefully recorded his construction of the information that he had been given soon after the birth: Beth was “perfectly-formed”, he wrote, an almost imperceptible proud smile momentarily revealing his emotional vulnerability. After making his lists, the columns were evenly balanced. “But, you haven’t included: ‘she’s alive, a person, she has the force of life’” I had pointed out. Both parents looked at me. The mother wiped a trickling tear from her cheek. “So, which column does that go in?” asked the father.

In the ensuing years some “certainties” have emerged in the field of neonatology: antenatal steroids, surfactant, and therapeutic hypothermia etc - all essentially proven advancements. However, the passage of time has left me no closer now than I was then to knowing, with any degree of certainty, either what is in the best interest for patients like Beth and others with indeterminate outcomes, or what processes are most appropriate to help resolve these issues.

There is, then, much work to be done in moving forward in our understanding and practice of ethical decision-making in neonatal care. Today, we are fortunate in having been able to convene an eminent Faculty for today’s conference who will, we hope, help us explore different aspects of ethical care of newborn babies from a range of different perspectives. In addition to the formal talks and forum discussion we have arranged both poster and platform case presentations, all of which, we hope, will afford the opportunity for discussion and sharing of experience.

We are very grateful to you all for taking time out to join us today and we do hope that you will find the day informative, helpful and enjoyable.

**Mike Hall**

Co-Organiser/Chair

European Neonatal Ethics Conference

## Professor Anneke Lucassen



Anneke Lucassen is Professor of Clinical Genetics at the University of Southampton and Consultant in the same at University Hospitals Southampton. She also currently holds the honorary 'Bijtel' Chair in Medicine at the University of Groningen, the Netherlands. Her interests lie in the application of new genetic technologies in clinical practice and in particular the ethical and legal issues that need to be considered in so doing. Through the CELS unit (Clinical Ethics and Law at Southampton: [www.soton.ac.uk/cels](http://www.soton.ac.uk/cels)), she takes part in interdisciplinary research, education and public engagement around genomic medicine. Anneke sits on the Nuffield Council of bioethics as well as the ethics advisory group for Genomics England and runs a national discussion forum for considering ethical issues in genetic practice. ([www.genethicsclub.org](http://www.genethicsclub.org))

## Mr Robert Wheeler



Mr Robert Wheeler is a Consultant Paediatric & Neonatal Surgeon at University Hospital Southampton (UHS); his main surgical interest is in paediatric oncology surgery, and the techniques of tumour dissection. He chaired the Surgical Section of the UK's Children's Cancer and Leukaemia Group (CCLG) 2009-2011. He holds the degree of LLB and is an Honorary Senior Lecturer in Clinical Law, with particular legal interests in consent and confidentiality in children. His (current) PhD research relates to the applicability of the legal doctrine *res ipsa loquitur* to the standard of care in operative surgery. He has contributed to a wide range of legal and medical journals and textbooks. He was also a member of the RCPCH working group which produced the "Framework for Practice", 2<sup>nd</sup> Ed published in 2004, entitled "Withholding and Withdrawing Life Sustaining Treatment in Children". Mr Wheeler is the inaugural Director of the Department of Clinical Law at UHS, the first such clinical department in the NHS. He has sat on the Ethics Committee of the British Medical Journal and chaired the Ethics and Law Committee of the RCPCH. He is chairman of the UHS Clinical Ethics Committee, and that of the British Association of Paediatric Surgeons.

## Dr Dominic Wilkinson



Dominic Wilkinson is 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 and Associate Professor of Neonatal Medicine and Bioethics at the University of Adelaide. 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 the widely-acclaimed book “Death or Disability? The ‘Carmentis Machine’”. He is also the author of “Decision-Making for Critically Ill Children” and co-author of an online handbook for parents “Caringdecisions” [www.rch.org.au/caringdecisions](http://www.rch.org.au/caringdecisions). He is Associate Editor of the Journal of Medical Ethics and Managing Editor of the Journal of Practical Ethics.

## Dr Angela Fenwick



Dr Angela Fenwick is a Senior Lecturer in Medical Ethics and Education. She is part of the CELS unit (Clinical Ethics and Law at Southampton: [www.soton.ac.uk/cels](http://www.soton.ac.uk/cels)), a research/ education group specialising in ethical and legal issues arising from genomic medicine. The output of the group is both academic and policy orientated with input into the development of national policy and guidelines for clinical practice, and also engages the public in the ethical issues impacting on health in society. Her particular interests include: the use/abuse of the body in medicine, medical decision making, and the limits of autonomy. Angela also co-ordinates the ethics and law teaching for the medical undergraduate and postgraduate programmes. She is a member of the Education Steering Committee of the Institute of Medical Ethics (IME) which developed core learning outcomes for ethics and law for all medical schools in the UK and she led the IME’s work on assessment in undergraduate medical education.



## Professor Pieter Sauer



Professor Pieter Sauer is emeritus Professor of Pediatrics, and former Chairman of the Department of Pediatrics, at the University Medical Center Groningen, Groningen, The Netherlands. He was Head of the Division of Neonatology, Department of Pediatrics, Sophia Children's Hospital, Rotterdam before moving to Groningen. He is a former President of the European Society for Paediatric Research and was European Chief Editor of the journal *Pediatric Research*. He was a member of the National Health Council for Holland and in 2011 was named "Officier in de orde van Oranje Nassau" by the Queen of The Netherlands. Professor Sauer has had a major research interest in the field of nutrition and metabolism of newborn infant and from 1995-2001 was Trustee and Chairman of the International Pediatric Research Foundation. He is author or co-author of some 229 publications in international peer reviewed journals. Professor Sauer is a former member of the Dutch Working Group for "Ethical Aspects of Neonatology" and was also the Dutch delegate for, and member of the Ethical Committee of, the Confederation of European Pediatric Specialists. With his colleague, Professor Eduard Verhagen, he was co-author of a paper entitled "The Groningen Protocol - Euthanasia in severely ill newborns" which was published in the *New England Journal of Medicine* in 2005. This has formed the basis for subsequent practice in Holland and ignited international debate about what is acceptable practice in the ending of life in infancy.

## Dr Marina Cuttini

Marina Cuttini is Director of the Perinatal Research Unit at the Bambino Gesù Children's Hospital in Rome. She trained in medicine at the University of Trieste, Italy, where she subsequently specialized in paediatrics and neonatology. In 1982-83 Dr Cuttini studied as Fulbright fellow at the School of Public Health of Harvard University, where she obtained her "Master of Public Health" degree. She holds a doctorate in Maternal and Child Medicine from the joint program of the Universities of Trieste and Torino. Dr Cuttini has previously held the appointments of Professor of Epidemiology & Biostatistics at the Medical School of Trieste University, and Director of the Unit of Epidemiology and Bioethics at the same Institute. She has sat as member of the Research Ethics Committee of the Maternal and Child Health Institute in Trieste and external member of the Ethics Committee of the WHO International Agency for Research on Cancer. Dr Cuttini's main research interests are in perinatal and pediatric epidemiology, follow-up of very preterm infants, quality of care evaluation and ethical aspects of care, and she is Scientific Advisor in a number of European collaborations relating to these areas. She was Italian coordinator of the E.U. project on "Parental visiting and involvement in the care of very low birthweight babies in Europe" and project leader of the E.U. EURONIC and EUROBS collaborations on ethical decision-making in neonatal intensive care and in obstetrics respectively.

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### Programme

#### Chair for Morning Session: Dr Mike Hall

- 09.30 - 10.00 “Genome testing at birth”  
Prof Anneke Lucassen
- 10.00 - 10.30 “Gestational ageism: when is non-resuscitation of extremely preterm infants permissible?”  
Dr Dominic Wilkinson
- 10.30 - 11.00 “Balancing interests in neonatology”  
Mr Robert Wheeler

#### *11.00 - 11.20*

#### *Coffee*

- 11.20 - 11.50 “End of life decisions in newborn infants-  
The Dutch experience”  
Prof Pieter Sauer
- 11.50 - 12.20 “End of life decisions in European NICU’s  
Results from the EPICE Study”  
Dr Marina Cuttini
- 12.20 - 12.50 Panel Discussion

#### *12.50 - 14.00*

#### *Lunch and poster presentations*

#### Chair for Afternoon Session: Dr Robert Ironton

- 14.00 - 15.15 “Case Presentations”  
Facilitator: Dr Angela Fenwick
- 15.15 - 16.00 “Is it ethical to withhold artificial feeding from newborn infants? If so, when?”  
Dr Dominic Wilkinson

#### *16.00 - 16.55*

#### *Tea Feedback and Close*

## ABSTRACTS - Podium

1. 'If there is no gut instinct' - the case of a neonate with total intestinal aganglionosis  
**Dr Susie Holt** - ST6 Palliative Care, Alder Hey Children's NHS Trust, Liverpool
2. Neonates with parents who are children: who consents?  
**Dr Helen Turnham** - PICU Grid Trainee Year 2, Great Ormond Street Hospital, London
3. CIs dehydration an ethical way of withdrawing care?  
**Dr Anna Paltrinieri** - Post CCT Clinical Fellow, Evelina Children's Hospital, London
4. Severe oligohydramnios and recurrent antepartum haemorrhages: termination of pregnancy request at 24 weeks gestation  
**Dr Ineke van Herwijnen** - ST3 Obstetrics and Gynaecology, Princess Anne Hospital, Southampton

## ABSTRACTS - Poster

1. Survey of perceptions of reorientation of care in tertiary neonatal unit  
**Dr Anushma Sharma** - ST6 Paediatrics, Bolton Hospital NHS Foundation Trust, Bolton
2. Do Words Matter?  
**Dr Alexandra Doerr** - ST6 Neonatal Grid Trainee, St Michaels Hospital, Bristol
3. Socioeconomic and Demographic Differences between Extremely Preterm infants who die and those who survive to discharge  
**Dr Nicola Medd** - SpR Year 5 Paediatrics, Sheffield Children's Hospital, Sheffield
4. Diagnostic and treatment decision of newborn with Myelomeningocela cervicalis and Hydrocephalus massiva  
**Dr Hajrije Ismaili** - Consultant, University Clinical Center of Kosovo, Kosovo
5. Service evaluation of end of life care over a one year period in a level three neonatal unit  
**Anne Bean** - ST3 Paediatrics, Sheffield Children's Hospital, Sheffield
6. Ethical Challenge in a NICU-An Experience with the family  
**Vishal Paisal** - Paediatric Cardiology Fellow, UHS, Southampton
7. 'Artificial Nutrition; Humane Symptom Relief or Prolonging the process of death?  
**Dr Carly Reynolds** - ST5 Paediatrics, Luton and Dunstable Hospital, Luton
8. 'K 's story-An Ethical Dilemma'  
**Dr Roopali Soni** - ST7 Neonatal Trainee, Leeds General Infirmary, Leeds
9. Neonatal Ethical dilemmas beyond Europe, an overview and a case presentation  
**Dr Zahreddin Abusalah** - Consultant Neonatologist, Medclinic, Dubai, UAE
10. Outcome of infants with birth weight less than 500 grams in a tertiary neonatal unit  
**Dr Kelly Brown** - ST7 Neonatal GRID Trainee, Queen Alexandra Hospital, Portsmouth

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