

17 - 19 SEPTEMBER 2014

6th National Paediatric Bioethics Conference

Things that keep us awake at night



DAY 1

Wednesday 17th September 2014

“Things that keep us awake at night”

12:00pm – 5:15pm – Ella Latham Auditorium, The RCH Melbourne

12:00pm	Conference registration
	CONFERENCE OPENING Session 1: Ground Rounds “Things that keep us awake at night” Chair: Prof Paul Monagle Stevenson Professor and Assistant Dean, RCH Academic Centre, University of Melbourne; Paediatric Haematologist, RCH
12:30pm	Conference Welcome Dr Hugo Gold Clinical Associate Professor, Paediatrician, Founding Clinical Director, Children’s Bioethics Centre, RCH
12:35-1:30pm	KEYNOTE ADDRESS <i>Moral distress, ethical uncertainty and mere tragedy</i> A/Prof Lynn Gillam Clinical Ethicist and Academic Director, Children’s Bioethics Centre, RCH
1:30–1.45pm	Break
	Session 2: Submitted papers Things that keep us awake at night - Moral Distress Chair: Prof Trevor Duke Director, Centre for International Child Health and Deputy Director, Paediatric Intensive Care Unit, RCH
1:45-2:15pm	<i>The management of complex behavioural issues in an adolescent female – a case of differing views and uncontrolled behaviour</i> A/Prof John Gall and Dr Anne Smith, Victorian Forensic Paediatric Medical Service (VFPMS) RCH, Department of Paediatrics, The University of Melbourne

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2:15-2:45pm	<p><i>End of Life Decision making - "to donate or to not donate" the ethical dilemmas encountered during paediatric Donation after Cardiac Death</i></p> <p>Ms Lyn Ireland Tissue Donor Coordinator, Donor Tissue Bank of Victoria Victorian Institute of Forensic Medicine</p>
2:45-3:15pm	<p><i>Dignity of Risk vs Duty of Care</i> <i>Management of a young adult with PWS Syndrome</i></p> <p>Dr Giuliana Antolovich Developmental Medicine & General Medicine, RCH, Honorary Fellow, Clinical Sciences, Developmental Disability and Rehabilitation, MCRI</p>
3:15-3:30pm	Discussion
3:30pm	Afternoon break
<p>Session 3: Advance Care Planning</p> <p>Chair: Dr Peter McDougall Executive Director Medical Services & Clinical Governance and Chief Medical Officer, RCH</p>	
3.45-5:15pm	<p><i>Advance Care Planning in Child and Adolescent Health: Planning ahead with parents</i> Dr Jenny Hynson Paediatrician, Medical Director, Victorian Paediatric Palliative Care Program, RCH</p> <p><i>Is the Operating Theatre a "Special Place"</i> <i>Advanced Care Directives and the Peri-anaesthetic Period</i></p> <p>Dr Giuliana C Antolovich Developmental Medicine & General Medicine, RCH, Honorary Fellow, Clinical Sciences, Developmental Disability and Rehabilitation, MCRI</p> <p><i>When Patients and Doctors disagree</i> A/Prof Charlie Corke Intensive Care Unit, Barwon Health</p> <p><i>Medical impasse: intractable disagreements about continuing life-sustaining treatments</i> A/Prof John Massie Respiratory Physician, Head of Education and Training, Respiratory Medicine, RCH</p>
5:15pm	Conclusion

DAY 1 - Evening The Annual Ethics Public Forum Ella Latham Auditorium and Café Adamo The Royal Children’s Hospital	
5:30pm	Welcome Reception (refreshments and canapés served) in Café Adamo
6:30pm	Guests move to Ella Latham Auditorium
6:40pm	Welcome
7:00 – 8.25pm	<p><i>How much say should young people have in their health care?</i></p> <p>The aim of the forum is to encourage public discussion about ethical issues related to the provision of health care for children and adolescents. These issues are of vital importance to whole community, not just to hospital staff. We particularly want to encourage young people to think about ethical issues associated with health care for people of their age group, and to express their views. Clinical staff and ethicists from the RCH and other institutions will be in the audience at the public forum, and value the opportunity to hear what young people have to say.</p> <p>The forum will be in the form of a question and answer session with panelists, members of the public, including secondary and post-secondary students and universities to encourage their voice in diversity of thought, experience and opinion. Audience members will be invited by the moderator to make comments or ask questions. Two case scenarios will be discussed.</p> <p>Moderated by A/Prof Lynn Gillam Academic Director , Children’s Bioethics Centre, RCH</p>
8:25pm	Concluding remarks Mr Barry Novy OAM Chair, Bioethics Development Board
8:30pm	Conclusion

DAY 2

Thursday 18th September 2014

“Things that keep us awake at night”

7:30am – 4:00pm – The RCH Melbourne

Session 4: “Coffee & Controversy”

Breakfast session sponsored by MSA

Chair: A/Prof Michael Marks

Chair, Royal Children's Hospital Medical Staff Association
(Vernon Collins Lecture Theatre)

7:45am –
8:45am

Case: *Three sick babies one NICU cot. Who should get the last bed?*

Dr Rod Hunt Director, Newborn Intensive Care Unit, RCH
Michael Stewart, John F Mills
Department of Neonatal Medicine, RCH

9.00-10.15am

Session 5: Concurrent Sessions

Session 5A:

Child's interests & Reproduction Technologies

Chair: A/Prof Brigid Jordan
Infant Mental Health Program, RCH
(Ella Latham Auditorium)

Session 5B:

Learning and doing ethics

Chair: A/Prof Clare Delany Senior Ethics Associate,
Children's Bioethics Centre, RCH
(Vernon Collins Lecture Theatre)

9:00am

*Avoiding the “Gammy dilemma”
Who is a good enough parent for IVF
treatment?*

Georgina Hall
PhD Student, Centre for Health and
Society (MSPGH) University of Melb;
Children's Bioethics Centre, RCH

**Panel discussion of 2 hypothetical
cases**

Panellists:
Marianne Tome IVF Counsellor,
Melbourne IVF
Sarah Jones Psychotherapist, Infant

*An Opportunity for Medical Students to Learn about
Ethical Issues in Paediatrics*

Nikki Kerruish Senior Lecturer, Department of
Women's and Children's Health and Bioethics Centre,
University of Otago

	mental health Facilitated by A/Prof Lynn Gillam	
9:30am		Workshop: <i>Doing ethics in a team</i> Sharyn Milnes, Deborah Porter Deakin University Ian Story Deakin University
10:15am	Morning break	
	Session 6: Open Disclosure Chair: TBC	
10:30am – 12.00pm	<p><i>Open disclosure: refining our approach</i></p> <p>Dr Meredith Allen Director, Medical Education, Consultant in Paediatric Intensive Care & Clinical Lead Quality and Patient Safety, RCH</p> <p><i>Knowledge & experience with families</i></p> <p>Marie Bismark University of Melbourne</p> <p><i>Should children or adolescents be recipients of open disclosure?</i></p> <p>Jennifer Morris</p>	
12:00pm	Lunch Break	
	Session 7: The art of not being a “difficult parent” Chair: Jayne Dullard Executive Director Communications, RCH	
12:30-1:30pm	<p>KEYNOTE ADDRESS</p> <p><i>The art of not being a “difficult parent”</i></p> <p>Dr Ruth Webster Research Fellow, Cardiovascular Division, Co-ordinator, SPACE Collaboration, Study Director, TRIUMPH, The George Institute for Global Health, Sydney</p>	
1:30–1:45pm	Break	

1:45 - 4:00pm		Session 8: Concurrent Sessions	
<p align="center">Session 8A:</p> <p align="center">Chair: Dr Hugo Gold</p> <p align="center">Clinical Associate Professor, Paediatrician, RCH (Ella Latham Auditorium)</p>		<p align="center">Session 8B: Fertility Preservation</p> <p align="center">Chair: A/Prof John Massie</p> <p align="center">Respiratory Physician, RCH (Vernon Collins Lecture Theatre)</p>	
1:45-2:15pm	<p>Case: <i>A Busy Intersection: Forensic Paediatric Medicine, Ethics and the Law</i></p> <p>Anne Smith Medical Director VFPMS RCH</p>	<p><i>"Don't ask, don't tell?": Managing Gender Dysphoria</i></p> <p>Dr Michelle Telfer Clinical Lead Adolescent Medicine Dr Debi Feldman Paediatrician Campbell Paul Porpavai Kasiannan Centre for Adolescent Health, RCH</p>	
2:15-2:45pm	<p><i>"I'm the surgeon and I'm calling the shots": Surgeons' experiences of denying parental requests for paediatric facial surgery</i></p> <p>Lauren Notini PhD Student, Centre for Health and Society (MSPGH) University of Melbourne; Department of Paediatrics, University of Melbourne; Children's Bioethics Centre, RCH</p>	<p>Case: <i>Fertility Preservation in Prepubertal Girls with a Malignancy</i></p> <p>Amanda Morris / Fertility Preservation Task Force, RCH</p>	
2:45pm	Afternoon Break		
3:00-3:30pm	<p><i>How did we end up arguing in favour of cosmetic labioplasty for teenagers?</i></p> <p>Dr Merle Spriggs Children's Bioethics Centre, RCH; Centre for Health and Society, University of Melbourne; Murdoch Childrens Research Institute</p>	<p><i>"The mum just said no": ethical issues when parents refuse fertility preservation</i></p> <p>Dr Rosalind McDougall Children's Bioethics Centre, RCH; Centre for Health Equity, University of Melbourne</p>	
3:30-4:00pm	<p><i>Telling the truth to children: Doctors' practices</i></p> <p>Nicholas Hudson The University of Melbourne</p>		
4:00pm	Conclusion		

DAY 3

Friday 19th September 2014

“Things that keep us awake at night”

8.30am – 3.15pm – Ella Latham Auditorium, The RCH Melbourne

Session 9: Genetics

Chair: Dr David Amor, Director, Victorian Clinical Genetics Services

8:30-10.00am	<p><i>Future autonomy, current technology: Ethics and next generation gene sequencing in children</i></p> <p>Dr Ainsley Newson Senior Lecturer in Bioethics, Centre for Values, Ethics and the Law in Medicine (VELIM) School of Public Health, The University of Sydney</p> <p>Case presentation: Dr Zornitza Stark Consultant Clinical Geneticist Dr Sue White Victorian Clinical Genetics Service</p>
10:00–10:30am	Morning break

Session 10: Concurrent Sessions

<p>Session 10A: End of Life Chair: TBC (Ella Latham Auditorium)</p>		<p>Session 10B: Chair: Dr Rosalind McDougall Research Fellow in Ethics Children's Bioethics Centre, RCH Melbourne School of Population and Global Health, University of Melbourne (Vernon Collins Lecture Theatre)</p>
10.30 am-11:00am	<p>Case Study: <i>Newborn with significant brain injury due to post-natal asphyxia</i></p> <p>Dr Rosalynn Pszczola Neonatologist, Sunshine Hospital, Western Health, Melbourne</p>	<p><i>The ethics of persuasion, inducement and coercion in paediatric physiotherapy practice</i></p> <p>A/Prof Clare Delany Senior Ethics Associate, Children's Bioethics Centre, RCH Dr Lynley Anderson Senior Lecturer, Bioethics Centre, University of Otago</p>
11:00am-11:30am	<p><i>Disclosure, communication, awareness and acceptance: The four hurdles in parents' understanding of medical futility</i></p> <p>Benjamin A. Vialle School of Medicine, University of Queensland, Mayne Medical School</p>	<p><i>Childhood Obesity Prevention: An Ethics Framework and Two Test Cases</i></p> <p>Tim Allen Centre for Human Bioethics, Monash University</p>

	Nikola A. Stepanov Melbourne Medical School and School of Global and Population Health, The University of Melbourne & School of Medicine, University of Queensland	
11:30am-12:00pm	<p><i>Understanding The Physical Stages of Dying to Support Families in Making Quality End of Life Choices for Their Dying Child</i></p> <p>Lea Rose Clinical Counsellor/ Psychotherapist Australian Counselling Association (ACA)</p>	<p><i>Who owns the swabs? Child & Adolescent Sexual Assault & Forensic Medical Examinations</i></p> <p>Anne Smith, Medical Director VFPMS RCH, Department of Paediatrics, The University of Melbourne</p>
12:00–12:30pm	Lunch Break	
Session 11:		
Chair: Dr Tom Connell Director/Paediatrician, General Medicine RCH		
12:30-1:30pm	<p>KEYNOTE ADDRESS</p> <p><i>Children, sport, health and ethics – a challenge for all paediatric health professionals</i></p> <p>Dr Lynley Anderson Senior Lecturer, Bioethics Centre, University of Otago</p>	
1:30–1:45pm	Break	
Session 12: Ethics and angry parents in real time		
Chair: TBA		
1:45-3:00pm	<p><i>Dealing with intense emotions when ethical values are at stake – A scenario-based session with trained medical actors</i></p> <p>Doctor: Wirginia Maxiner, Neurosurgeon Nurse: TBA</p> <p>The scenario:</p> <p>14 year old girl with a brain tumour, with a very poor prognosis. Her parents refuse to allow her to be told anything about her diagnosis or prognosis. Medical and nursing staff strongly believe she has a right to know, and is distressed by her lack of understanding of what is happening to her.</p> <p>Facilitated by A/Prof Lynn Gillam Academic Director , Children’s Bioethics Centre, RCH</p>	
3:00–3:15pm	<p>Close</p> <p>New Clinical Director, Children’s Bioethics Centre</p>	