

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



DAY 1 Wednesday 6 September

9:00am	Conference registration Ella Latham Auditorium foyer
9:45am-10:00am	Conference opening and Welcome Ella Latham Auditorium
	Welcome to Country - Elder
10:00am	Session 1: Tensions, conflicts and disagreements Ella Latham Auditorium
10:00-10:30am	Family centred care may stonewall clinical decision-making – experiences from a UK clinical ethics committee Dr Carolyn Johnston Lecturer, Health Law & Ethics, Medical School, Deakin University
10:30-11:00am	Different Shades of Grey: When parents do not act in their child's best interests A/Prof Chan Mei Yoke Specialist in Palliative Medicine, Senior Consultant and Head, Haematology/Oncology Service & Paediatric Palliative Service, KK Women's and Children's Hospital, Singapore
11:00-11:30am	Access to Ultra Expensive Therapies – Ethical conundrums around community advocacy Dr Erin F Sharwood , Helen Irving, James McGill, David Levitt, Tony Huynh Lady Cilento Children's Hospital, Brisbane
11:30-12.30pm	Lunch Break

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



12:30-1:30pm	Session 2: Keynote address (Grand Rounds) Ella Latham Auditorium
	Patient and Family-Centred Care: is paediatric health care losing sight of the patient? Prof Randi Zlotnik Shaul , Director of Bioethics, The Hospital for Sick Children Department of Paediatrics, Joint Centre for Bioethics, The University of Toronto
1:30-1.45pm	Break
1:45-3:15pm	Session 3: Engaging with families outside the clinical context Ella Latham Auditorium
1:45-2:05pm	When the hospital is home Dr Joshua Osowicki , General Paediatrician, Paediatric Infectious Diseases Physician, PhD student; Group A Streptococcus Research Group, Murdoch Childrens Research Institute; Department of Infection and Immunity, Monash Children's Hospital, Melbourne; Department of Paediatrics, University of Melbourne; Dr Tammy Goldwasser , Advanced Trainee – General Paediatrics, Infant Mental Health Unit, Department of Psychiatry, The Royal Children's Hospital
2:05-2:25pm	Ms Laura Toscano Overview of study data at the Royal Children's Hospital
2:25-2:45pm	Staff attendance at patient funerals: Testing our intuitions about child and family-centred care? Dr Lauren Notini , Postdoctoral Fellow in Clinical and Organizational Bioethics, Joint Centre for Bioethics, University of Toronto; Prof Randi Zlotnik Shaul , Director, Bioethics Department, The Hospital for Sick Children; Member, Joint Centre for Bioethics, University of Toronto
2:45-3:15pm	Multidisciplinary Panel: A/Prof Jenny Hynson , Clinical Associate Professor; Head, Victorian Paediatric Palliative Care Program, The Royal Children's Hospital Ms Robyn Clark , Social Worker, Social work, The Royal Children's Hospital; Nurse TBA
3:15-3:45pm	Afternoon break

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



3:45-4:45pm	Session 4: Decision-making for premature babies Ella Latham Auditorium
3:45-4:15pm	Analysis of decision-making in the 'grey zone' in extremely premature infants: a comparison of different ethical approaches Ms Alice Cavolo & Dr Danya F Vears Center for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven, Leuven, Belgium
4:15-4:45pm	Whatever decision you make, it will be the right one: the experience of difficult decision-making as a parent of a baby born prematurely Ms Jenny O'Neill Clinical Nurse Consultant, Neurodevelopment and Disability, The Royal Children's Hospital; PhD candidate, The Department of Paediatrics, The University of Melbourne
4:45pm	Conclusion

6:00-10:00pm	Conference dinner The Woodward Centre, Level 10 Law Building, University of Melbourne 185 Pelham Street, Carlton
	Food for thought: Same condition, different treatment on experimental and expensive new treatments. Who pays, who decides, who comes next? Prof Lynn Gillam , Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital Prof Lynn Gillam will engage dinner guests in a lively case discussion with interactive audience opinion poll.

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



DAY 2 Thursday 7 September

7:45-8:45am	Session 5: Breakfast session proudly sponsored by the Medical Staff Association (MSA) RCH Foundation, Family Resource Centre, Level 2, 48 Flemington Road Chair: A/Prof Jill Sewell , Paediatrician, Centre for Community Child Health; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne; Chair, Victorian Clinical Council; President, Australian Medical Council	
	Moral distress for clinicians: how do we support families and stop doctor shopping? Dr Margie Danchin Paediatrician, Department of General Medicine, The Royal Children's Hospital Senior Research Fellow, Vaccine and Immunisation and Rotavirus Research Group, Murdoch Childrens Research Institute Senior Fellow, Department of Paediatrics, The University of Melbourne	
Sessions 6: Concurrent Sessions		
10:00-11:30am	Session 6A: Different voices & stories in patient and family-centred care Ella Latham Auditorium	Session 6B: Patient and family-centred care for Adolescents Vernon Collins Lecture Theatre
10:00-10:30am	Truth, Justice and the Australian Way- Difficult Transplantation Considerations in a Complex Patient story Dr Shivanthan Shanthikumar A/Prof John Massie Respiratory Medicine, The Royal Children's Hospital; Department of Paediatrics, University of Melbourne; Respiratory Diseases, Murdoch Childrens Research Institute	Implementing the 'rights' of the adolescent patient in an inpatient unit Miss Melissa Anania , Associate Nurse Unit Manager, Kelpie Ward, The Royal Children's Hospital
10:30-11:00am	Whose voice is loudest? Ms Kate Nield , Social Worker Ms Justine Schutz , Social Worker Department of Social Work, The Royal Children's Hospital	The Voice of the Child and Adolescent in Clinical Decision Making – is it heard? Ms Marie Lobidel and Dr Vick Xafis Clinical Ethics, The Sydney Children's Hospitals Network

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



11:00-11:30am	<p>Rounding off the sharp edges of services – everyone has their story</p> <p>Mr Paul Pritchard, Senior Project Officer, Centre for Community Child Health, The Royal Children's Hospital</p>	<p>The gap between “child” and “family” when growing up with a disability <i>You Get Proud By Practising: Navigating Adolescence with a Disability</i></p> <p>Facilitator: Dr. Kate Irving Uncle Bob's General Neurology Fellow, The Royal Children's Hospital</p> <p>Panelists: Ms Jax Jacki Brown and Ms Carly Findlay</p>
11:30am-12:30pm	Lunch Break	
12:30-1:30pm	<p>Session 7: Plenary session</p> <p>Ella Latham Auditorium</p>	
	<p>Ethical challenges in transition to adult care</p> <p>Ms Evelyn Culnane, Manager, Transition Support Service, The Royal Children's Hospital</p> <p>Moderated by A/Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre; and Dr Rosalind McDougall, Research Fellow in Ethics, Children's Bioethics Centre, The Royal Children's Hospital</p> <p>Multidisciplinary Panel:</p> <p>Ms Evelyn Culnane, Manager, Transition Support Service, The Royal Children's Hospital Dr Giuliana Antolovich, Consultant Paediatrician, Developmental Medicine & Department of General Medicine, The Royal Children's Hospital; Honorary Fellow, Murdoch Childrens Research Institute Ms Jacqui Leverett, Former RCH patient Mrs Sue Kennedy, Mother of current RCH patient, Brooke Kennedy</p>	
1:30-1.45pm	Break	

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



1:45-3:00pm	Session 8: Parents as partners in care Ella Latham Auditorium
1:45-2:30pm	RCH parents discuss their evolving role as partners in care Facilitated by Prof Lynn Gillam , Clinical Ethicist and Academic Director and A/Prof Jill Sewell , Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital
2:30-3:00pm	Helping or harming? The use of force in paediatric medical procedures and the role of parents Dr Liz Bishop Michael Kirby Centre for Public Health and Human Rights, Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine; Chairperson, Haemophilia Auxiliary, Monash University, Melbourne Dr Angela Mackenzie , Paediatrician, www.everybodystaycalm.com
3:00-3:30pm	Afternoon break
3:30-5:00pm	Session 9: Patient and family-centred care in the community Ella Latham Auditorium Chair: Prof Lynn Gillam , Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital
3:30-4:00pm	Family-centred practice in human services: Learnings from a parallel professional world Mr Tim Moore Senior Research Fellow, Centre for Community Child Health, The Royal Children's Hospital
4:00-4:30pm	Childhood obesity: is there a role for child protection – a comparison of two cases Ms Daniella Tassoni Paediatric Dietitian, Nutrition and Food Services Department, The Royal Children's Hospital A/Prof Matthew Sabin , Chief of Medicine, Director of Endocrinology, Diabetes and Obesity; The Royal Children's Hospital Dr Zoe McCallum , Consultant Paediatrician, Weight Management Service & Department of Gastroenterology and Clinical Nutrition, The Royal Children's Hospital
4:30-5:00pm	Cases that discuss some irreconcilable dilemmas regarding family centred care - when the child's interests may be deemed to be contrary to the parents demands Dr Ben Goodfellow , Infant, Child and General Psychiatrist, Geelong University Hospital

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



DAY 3 Friday 8 September

Sessions 10: Concurrent Sessions

10:00-11:30am	Session 10A: Life and death issues Ella Latham Auditorium	Session 10B: The importance of partnerships with parents Vernon Collins Lecture Theatre
10:00am-10:30am	Disagreement between parents and doctors in the context of the Oshin Kiszko case Ms Caitlin Tobin , Solicitor, Lander & Rogers Lawyers, Melbourne	Sharing the process: exploring partnership in the parent: professional relationship Ms Leonie Symes , Manager – Training and Development, Centre for Community Child Health, The Royal Children's Hospital
10:30am-11:00am	Striking the right balance: Is the pendulum swinging too far? Dr Vicki Xafis , The Sydney Children's Hospitals Network; Sydney Health Ethics, The University of Sydney; Discipline of Obstetrics and Gynaecology & Discipline of Public Health, The University of Adelaide	After the Shock of Diagnosis, Complacency Sets In Ms Flora Pearce , Department of Metabolic Medicine & Social Work, The Royal Children's Hospital; Ms Erin Mullane , Department of Metabolic Medicine & Department of Nutrition and Food Services, The Royal Children's Hospital
11:00am-11:30am	Patient-Centered Care in Paediatric Intensive Care at End of Life – Are There Any Limits? Dr Shreerupa Basu , General Paediatric and Paediatric Intensive Care Advanced Trainee Paediatric Intensive Care Unit Children's Hospital Westmead	Ms Linda Sheahan
11:30-12:30pm	Lunch Break	

6-8 SEPTEMBER 2017

9th National Paediatric Bioethics Conference

Patient and family-centred care: Reality or Rhetoric?



12:30-2:15pm	Session 11: Plenary session Ella Latham Auditorium
	<p>Family violence: how to provide family centred care when there is domestic violence</p> <p>Hypothetical:</p> <p>Prof Lynn Gillam, Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital</p> <p>Panel:</p> <p>Ms Dani Gold, Senior Social Worker, Family Violence Project Officer, Social Work Department, The Royal Children's Hospital</p> <p>Expert commentators and member of the Victorian Police Force</p>
2:15-2:30pm	Closing remarks & Conference close A/Prof Jill Sewell , Clinical Director, Children's Bioethics Centre, RCH