



7-9 SEPTEMBER 2016

8th National Paediatric Bioethics Conference

Navigating uncertainty

**Melbourne
Children's**
A world leader
in child and
adolescent
health



Welcome

Dear colleagues,

On behalf of the Children's Bioethics Centre at The Royal Children's Hospital (RCH), it is with great pleasure that we welcome you to the 8th National Paediatric Bioethics Conference, in Melbourne.

This year's theme is 'Navigating uncertainty'. Caring for children and adolescents with serious medical conditions involves all sorts of uncertainties — about the long-term outcomes for children in intensive care, about effectiveness of new drugs, about getting a transplant in time, about the level of physical or psychological distress of a child who is unable to communicate. All of these make it harder to come to an ethical decision about what is in the best interests of the child.

The conference program tackles these ethical issues from many and varied angles and promises to be as engaging and thought-provoking as ever.

We welcome visitors to our hospital and its world-class facilities and are grateful to our organising committee, conference presenters and our local, national and international delegates.

We would like to acknowledge the generous support of our conference sponsors and the Bioethics Development Board chaired by Mr Barry Novy OAM.

The Children's Bioethics Centre acknowledges the generous ongoing support of the RCH Foundation.

We hope you enjoy this exciting program of events.

Sessions will be held at:

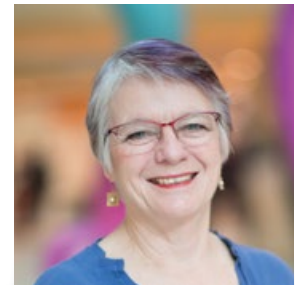
- **Ella Latham Auditorium**
Ground floor, West Building
- **Vernon Collins Lecture Theatre**
Health Education & Learning Precinct
Level 1, West Building
(via the Yellow lifts)

The Royal Children's Hospital Melbourne
50 Flemington Road, Parkville
Telephone (03) 9345 5522



Prof Lynn Gillam

Clinical Ethicist and
Academic Director
Children's Bioethics Centre
The Royal Children's Hospital



A/Prof Jill Sewell

Consultant Paediatrician;
Clinical Director
Children's Bioethics Centre
The Royal Children's Hospital

The Children's Bioethics Centre

The Children's Bioethics Centre is committed to promoting the welfare and rights of children and their families, by assisting in decision-making in complex health care situations. This involves helping to facilitate ethical reflection, promote good communication, resolve ethical conflict, and ease moral distress.

The Children's Bioethics Centre has four major areas of activity: a clinical ethics service, an education program, a research program, and development of guidelines and clinical procedures.

The Clinical Ethics Service offers clinical staff at the RCH advice and support in ethically challenging patient-care matters. A Clinical Ethics Response Group meeting is convened within 24-48 hours of a referral, and provides a structured forum for deliberation, with formal documentation. This service is highly valued and frequently used by hospital staff.

The work of the Children's Bioethics Centre was internationally recognised with the Hans-Joachim Schwager Award for Clinical Ethics Consultation in 2013.

The Centre is proudly supported by The Royal Children's Hospital Foundation.



The Bioethics Team

Front: A/Prof John Massie
Prof Lynn Gillam
A/Prof Jill Sewell

Back: A/Prof Clare Delany
Dr Rosalind McDougall
Ms Karen Fellows
Dr Merle Spriggs

Absent: Dr Jenny Hynson

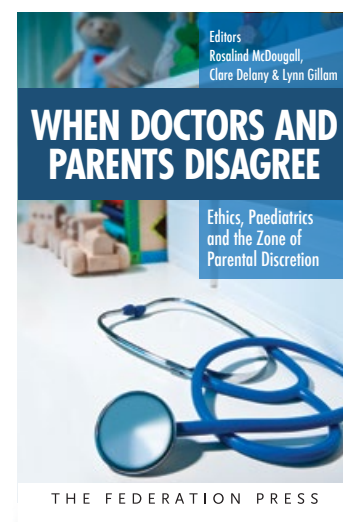
When should clinicians override parents' decisions about a child's medical treatment?

A feature of this year's conference is the launch of a new book: *When doctors and parents disagree*. The book is co-edited by Children's Bioethics Centre staff Rosalind McDougall, Clare Delany and Lynn Gillam.

This book answers this question by developing and exploring the zone of parental discretion: an ethical tool that aims to balance children's wellbeing and parents' rights to make medical decisions for their children. The tool is designed to assist clinicians when there is an entrenched disagreement with parents about the appropriate medical treatment for the child.

The book applies the tool in diverse paediatric clinical contexts, presents detailed analyses of cases, and provides guidance to clinicians facing these types of situations. Both parental requests for treatment and parental refusals of treatment are covered.

www.whendoctorsandparentsdisagree.com



Keynote speakers

Wednesday 7 September

Technological interventions in children with profound disabilities:
Navigating family and professional values

Professor Benjamin S. Wilfond MD

Parental requests for gastrostomies, tracheostomies, or assisted ventilation in children with profound disabilities raise ethical concerns about children's interests, parental decision-making, and health care costs. The underlying concern for many relates to the perceived value for these children. Clinicians should make efforts to appreciate the family's perspective regarding children with profound disabilities who require respiratory and nutritional medical support.

Finding opportunities to learn about the family members' lives outside of the health care setting may facilitate a deeper understanding of what it means to live with a child who has profound disabilities. In conversations with families, referring to interventions as futile and conditions as lethal will obscure the value-based nature of these decisions. Respiratory and nutritional interventions are not clearly against the interests of most children. Health care costs are a serious societal issue; however, the costs associated with profound disabilities are not the most significant contributor. Societal decisions not to provide life-sustaining health care to children with profound disabilities would require a public process.

Clinicians may have personal views regarding decisions for their own family or for their vision for society. However, clinicians have professional obligations to families who have different values. It is important to present balanced information and support parental decision-making so parents may decide to forgo or use life-sustaining interventions according to their values and goals.

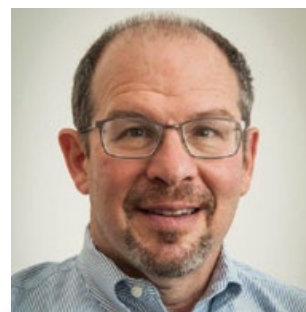
Biography:

Ben Wilfond is the director of the Treuman Katz Center for Pediatric Bioethics and a pulmonologist at Seattle Children's Hospital. He is professor and chief of the Division of Bioethics, Department of Pediatrics and an adjunct professor in the UW Department of Bioethics and Humanities, University of Washington School of Medicine.

He has close to 30 years experience on institutional review boards, data monitoring committees, and bioethics consult services. His scholarship focuses on ethical and policy issues related to the boundaries between research and clinical care.

His current projects address genomic testing for reproductive purposes, decision-making about children with disabilities, ethics consultation for clinical research, and informed consent about research on medical practices.

He is the immediate past president of the Association of Bioethics Program Directors, co-chair of the Pediatrics Working Group for the NHGRI Clinical Sequencing Exploratory Research Consortium, chair of the CTSA Clinical Research Ethics Consultation Collaborative, and research ethics case co-editor of the American Journal of Bioethics and a member of the NIH Societal and Ethical Issues in Research Study Section. He has served on the American Academy of Pediatrics Committee on Bioethics, the American Society of Human Genetics Social Issues Committee, and the American Thoracic Society Bioethics Taskforce. He is an elected member of the American Pediatric Society and a fellow of the Hastings Center.



Friday 9 September

Inevitability and honesty: The case for bedside rationing

Dr Melanie Jansen B. Med, MA (Phil)

Rationing is the process by which a finite resource is distributed. In the philosophical and economics literature, the rationing of healthcare resources is widely accepted as both ubiquitous and unavoidable, with discussion mainly focusing on what system of rationing is most just. In the medical literature, there is broad acceptance of the need to ration healthcare at a political or system level, but there is concern about the ethical difficulties inherent in bedside rationing.

In this presentation, I draw on Norman Daniels' work to devise a just system for rationing, using the Paediatric Intensive Care Unit as a case example. I will present evidence from empirical studies on healthcare professionals' attitudes to and experience of bedside rationing, exploring the tension between doctors' obligations to individual patients and to the broader community.

I conclude that Daniels' focus on procedural justice is appropriate both for system level and bedside rationing decisions. Using this approach has significant implications for the traditional identity of doctors and the therapeutic doctor-patient relationship, but I propose that ultimately this will be a positive change.

Biography:

Melanie Jansen is an Advanced Trainee in Paediatric Intensive Care Medicine and General Paediatrics and an ICU Registrar at the Gold Coast University Hospital. She is also the Clinical Ethics Fellow and a Steering Group Member at the Centre for Children's Health Ethics and Law (CCHEL), Queensland Children's Hospital. Melanie is a conjoint Lecturer at the University of Queensland School of Medicine.



Hypothetical: Dealing with the 'R' words — Rationing and Resources. Are we up for it?

Prof Lynn Gillam BA (Hons) MA (Oxon) PhD

Resource allocation at the bedside feels like the final frontier in clinical ethics — the thing that is hardest to think about, let alone speak about openly. Could it ever be right to take into account the cost when making treatment decisions about an individual child? After all, this could mean denying a particular form of treatment to a child when they might have benefitted from it. This goes against the ethical principle that lies at the heart of paediatric health care — to act in the child's best interests.

On the other hand, it is a brute fact that resources in a publicly funded health care system just are limited: giving an expensive or scarce treatment to one child can mean that another child misses out. Sometimes we cannot act in the best interests of both children. This hypothetical will explore these issues through an interactive discussion of realistic clinical scenarios.

Biography:

Lynn Gillam is an ethicist with particular interests in paediatric clinical ethics, research ethics and ethics education. Lynn is the Clinical Ethicist and Academic Director of the Children's Bioethics Centre at The Royal Children's Hospital Melbourne. Lynn is also Professor in Health Ethics in the School of Population Health at the University of Melbourne.



Day 1 Wednesday 7 September

12:00pm Conference registration
Ella Latham Auditorium foyer

12:30-1:30pm **Session 1: Conference opening and Welcome (Grand Rounds)**
Ella Latham Auditorium
Chair: Dr Peter McDougall, Executive Director Medical Services and Clinical Governance,
The Royal Children's Hospital (RCH) Melbourne

Welcome to Country
Elder Aunty Diane Kerr

Keynote address

**Technological interventions in children with profound disabilities:
Navigating family and professional values**

Prof Benjamin S. Wilfond, MD, Director, Treuman Katz Center for Paediatric Bioethics,
Seattle Children's Hospital, USA

1:30-1:45pm Break

1:45-3:30pm **Session 2: Advance care planning**
Ella Latham Auditorium
Chair: A/Prof Helen Irving, Pre-eminent Specialist and Clinical Lead, Centre for Children's Health Ethics
and Law (CCHL), Children's Health Queensland Hospital and Health Service, Brisbane
Associate Professor, University of Queensland, School of Medicine

Clinicians' perspectives on helpful resources for advance care planning
Dr Bronwyn Sacks, Paediatric Palliative Care Physician, Victorian Paediatric Palliative Care Program (VPPCP)

Parents' perspective on planning ahead
Mrs Shari Gotch and **Mrs Jess Holmes**

Developing a new approach to advance care planning
Dr Molly Williams, Paediatric Palliative Care Registrar, Victorian Paediatric Palliative Care Program (VPPCP),
Paediatric Oncologist, RCH

A resource for parents for advance care planning
A/Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre, RCH

3:30pm Afternoon break

3:45–4:45pm

Session 3: Ethics beyond the hospital

Ella Latham Auditorium

Chair: A/Prof Hugo Gold, Founding Clinical Director, Children's Bioethics Centre, RCH

3:45–4:15pm

Parents refusing treatment for a child's cancer – what happens when doctors go to court?

Prof Michael Sullivan, Paediatric Oncologist, Head of Solid Tumours and Neuro-Oncology, Children's Cancer Centre, RCH

Dr Charlotte Burns, Honorary Paediatric Oncology Fellow, Children's Cancer Centre, RCH

4:15–4:45pm

Ethical considerations arising from interactions with the media

Prof David Isaacs, Senior Staff Specialist, Department of Infectious Diseases and Microbiology, Clinical Professor in Paediatric Infectious Diseases, University of Sydney, The Children's Hospital at Westmead
A/Prof Henry Kilham, Dr Vicki Xafis, Clinical Ethics, Sydney Children's Hospitals Network

4:45pm

Conclusion

6:30–10:00pm

Conference dinner and hypothetical

The Mercure Hotel

Corner Flemington Road and Harker Street, North Melbourne

Is it ethical to 'correct' a child's appearance?

Prof Lynn Gillam, Clinical Ethicist and Academic Director, Children's Bioethics Centre, RCH

Two babies are born with unusual physical appearance — one facial, the other genital.

Is medical intervention to 'correct' or 'normalise' appearance ethically justifiable in either case?

Does the answer depend on anything other than the physical risks to the baby of the intervention?

Prof Lynn Gillam will engage dinner guests in a lively debate.

Day 2 Thursday 8 September

7:45–8:45am

Session 4: Breakfast session

Sponsored by the Medical Staff Association (MSA)

Health Education & Learning Precinct (HELP) Lounge, Level 1

Chair: **Dr Chris Barnes**, Chair MSA; Director, Haemophilia Treatment Centre, Clinical Haematology, RCH

Complex patients, complex decisions

Dr Tom Connell, Director, General Medicine, RCH

9:00-10:10am

Session 5: Fertility preservation

Ella Latham Auditorium

Chair: Mr John Stanway, Deputy Chief Executive Officer, Executive Director Clinical Operations, RCH

Aiming to preserve fertility for children receiving chemotherapy — medical options

Dr Yasmin Jayasinghe, Paediatric and Adolescent Gynaecology, RCH

Is it really ethically acceptable to offer experimental fertility preservation for young children?

Dr Rosalind McDougall, Research Fellow in Ethics, Children's Bioethics Centre, RCH

Prof Lynn Gillam, Clinical Ethicist and Academic Director, Children's Bioethics Centre, RCH

10:10-10:30am

Morning break

Session 6: Concurrent sessions

10:30-11:25am

Session 6A: Children and adolescents' views

Ella Latham Auditorium

Chair: Dr Rosalind McDougall, Research Fellow, Children's Bioethics Centre, RCH

Session 6B: Moral distress

Vernon Collins Lecture Theatre

Chair: A/Prof Jill Sewell, Consultant Paediatrician; Clinical Director, Children's Bioethics Centre, RCH

10:30-10:55am

It's important to let the child know what's going on: Exploring young adults' experiences of receiving information about their diagnosis of cystic fibrosis throughout childhood

Ms Emily Allen, Masters candidate, the University of Melbourne

Why we need moral distress in the midst of uncertainty: Healthcare professionals' perspectives

Dr Trisha Prentice, Neonatal Consultant, RCH; PhD candidate, the University of Melbourne

11:00-11:25am

The eleven-year-olds who want to have their legs amputated

Dr Merle Spriggs, Research Fellow, Children's Bioethics Centre, RCH; Melbourne School of Population and Global Health, the University of Melbourne; Murdoch Childrens Research Institute

Case discussion: Commencement of high flow oxygen therapy on the Dolphin ward

Ms Vikki Sanders, Clinical Nurse Specialist, Dolphin Ward, RCH

11:30am-1:00pm

Session 7: Plenary Session

Medicinal cannabis for children — long overdue or too far too soon?

Ella Latham Auditorium

Chair: Dr Peter McDougall, Executive Director Medical Services and Clinical Governance, RCH

Audience participation by 'Poll Everywhere'. Please download the free app onto your iPhone, iPad or Android phone via the link <https://www.polleverywhere.com/mobile>

Are you in favour of allowing some RCH patients access to medicinal cannabis?

What do others think? Will you change your mind during this session?

Legislative framework for access to medicinal cannabis in Victoria

Mr Matthew McCrone, Director, Medicinal Cannabis and RTPM Taskforces Regulation and

Ms Margot Johnson, Director, Office of Medicinal Cannabis, Department of Health and Human Services

Medicinal cannabis and epilepsy: The evidence

Dr Jeremy Freeman, Neurologist, Department of Neurology, RCH

Treating children with medicinal cannabis: A clinical perspective

Dr Mark MacKay, Consultant Neurologist, Department of Neurology, RCH

1:00-2:00pm	Lunch break	
Session 8 Concurrent sessions		
2:00-3:00pm	Session 8A: Gender dysphoria Ella Latham Auditorium Chair: Dr Merle Spriggs , Research Fellow, Children's Bioethics Centre, RCH	Session 8B: Promoting the child's wellbeing in difficult circumstances Vernon Collins Lecture Theatre Chair: Ms Annabelle Mann , Senior Legal Counsel, Legal Services, RCH
2:00-2:30pm	Moral dilemmas in the management of gender dysphoria Dr Porpavai Kasiannan , Consultant Psychiatrist, Mid West Community Team, Mental Health, RCH Dr Campbell Paul , Gender Service, RCH	What does a 'good procedure' look like? Ms Beth Dun and the Educational Play Therapy Team , RCH
2:30-3:00pm	Will changing my voice, change who I am? The uncertainty of voice training with transgender adolescents Ms Alessandra Giannini , Senior Speech Pathologist, Gender Dysphoria Team, RCH	Co-ordinated preparation for scoliosis surgery for children with developmental disability Ms Jenny O'Neill , Clinical Nurse Consultant, Developmental Disabilities, Developmental Medicine, RCH; A/Prof John Massie , Paediatric Respiratory Physician, Respiratory Medicine, RCH; Ms Donna Peachey , Scoliosis Nurse Coordinator, Orthopaedics, RCH
3:00-3:15pm	Afternoon break	
Session 9: Concurrent sessions		
3:15-4:45pm	Session 9A: Parents and doctors disagreeing Ella Latham Auditorium Chair: A/Prof Clare Delany , Clinical Ethicist, Children's Bioethics Centre, RCH	Session 9B: New and complex treatments Vernon Collins Lecture Theatre Chair: A/Prof John Massie , Paediatric Respiratory Physician, Respiratory Medicine, RCH
3:15-3:45pm	The zone of parental discretion: An ethical tool for navigating disagreement between parents and clinicians Dr Rosalind McDougall , Children's Bioethics Centre, RCH; Melbourne School of Population and Global Health, University of Melbourne	Expensive treatment for rare childhood disorders: Is achieving justice possible? Prof David Isaacs , The Children's Hospital at Westmead A/Prof Henry Kilham, Dr Vicki Xafis, Clinical Ethics, Sydney Children's Hospitals Network
3:45-4:15pm	Uncertainty — a case analysis Dr Nikki Kerruish , Senior Lecturer, Department of Women's and Children's Health and Bioethics Centre, University of Otago, Dunedin, NZ	Do they still have SMA type 1? Ms Robin Forbes , Victorian Clinical Genetics Service; Department Neurology, RCH; Murdoch Childrens Research Institute
4:15-4:45pm	The paediatric consultation in the 21st Century: Who is the expert? Dr Giuliana Antolovich , Consultant Paediatrician, Developmental Medicine and Department of General Medicine, RCH; Honorary Fellow, Murdoch Childrens Research Institute	Risky business: Ensuring safety for vulnerable children with complex care needs Ms Sarah Connolly , Manager Social Work, Aboriginal Health and Pastoral Care Services, RCH Ms Nicola Watt , Program Manager for Vulnerable Children and Aboriginal Health, Social Work, RCH

Day 3 Friday 9 September

9:15-10:30am

Session 10: Ethical challenges of new genomics

Ella Latham Auditorium

Chair: Prof Martin Delatycki, Clinical Director, Victorian Clinical Genetics Services; Director, Bruce Lefroy Centre for Genetic Health Research, Murdoch Childrens Research Institute

Disclosing incidental findings from genomic testing — the 'benefit to family' rationale

Prof Benjamin S. Wilfond, MD, Director, Treuman Katz Center for Paediatric Bioethics, Seattle Children's Hospital

10:30-10:45am

Morning break

Session 11: Concurrent sessions

10:45-11:35am

Session 11A: Things that keep us awake at night

Ella Latham Auditorium

Chair: Dr Guiliana Antolovich, Consultant Paediatrician, Developmental Medicine and Department of General Medicine, RCH

Session 11B: Patients from the outside

Vernon Collins Lecture Theatre

Chair: A/Prof Jill Sewell, Consultant Paediatrician, Clinical Director, Children's Bioethics Centre, RCH

10:45-11:10am

Case discussion: Baby K

Dr Jacqueline Duc, Palliative Care Fellow, Paediatric Palliative Care Service, Children's Health Queensland Hospital and Health Service; Centre for Children's Health Ethics and Law, Brisbane, QLD, Associate Lecturer, School of Medicine, University of Queensland

Can planned neonatal palliative care ever be a part of prenatal management?

Dr Paul Shekleton, Fetal Diagnostic Unit, Department of Obstetrics, Monash Health

11:10-11:35am

Assessing risk to future children born from IVF: Should pre-parents have the same rights as parents?

Ms Georgina Hall, PhD Candidate, Melbourne School of Population and Global Health, the University of Melbourne

Hail Mary Tourism: Caring for faces in the crowd

Dr Ari Horton, Paediatric Cardiology Fellow, Queensland Paediatric Cardiac Service, Queensland Children's Hospital, Brisbane

Dr Melanie Jansen, Clinical Ethics Fellow, Centre for Children's Health Ethics & Law, Queensland Children's Hospital, Brisbane

11:35am-12:30pm

Lunch break

12:30-1:50pm

Session 12: Plenary session — Waiting for a heart transplant

Ella Latham Auditorium

Chair: Prof Lynn Gillam, Clinical Ethicist and Academic Director, Children's Bioethics Centre, RCH

Waiting for a heart transplant: The role of Ventricular Assist Devices (VAD)

A/Prof Michael Cheung, Director, Department of Cardiology, RCH

Dr Jacob Matthew, Consultant Cardiologist, Department of Cardiology, RCH

A family perspective on waiting for transplant

Ms Allison Gillam and **Mr Callum Gordon**

1:50-2:10pm

Afternoon break

2:10-4:00pm

Session 13: Rationing of limited resources

Ella Latham Auditorium

Chair: Prof Trevor Duke, Director, Centre for International Child Health;
Deputy Director, Paediatric Intensive Care Unit, RCH

2:10-2:50pm

Inevitability and honesty: the case for bedside rationing

Dr Melanie Jansen, Clinical Ethics Fellow, Centre for Children's Health Ethics and Law,
Queensland Children's Hospital, Brisbane

2:50-3:45pm

Hypothetical: Dealing with the 'R' words — Rationing and Resources. Are we up for it?

Prof Lynn Gillam, Clinical Ethicist and Academic Director, Children's Bioethics Centre, RCH

3:45-4:00pm

Closing remarks and conference close

A/Prof Jill Sewell, Clinical Director, Children's Bioethics Centre, RCH

Notes



Proudly supported by

Mr David and Mrs Mira Kolieb and family

Mr Barry Novy OAM and Ms Sue Selwyn

The Debbie Stach Memorial Gift Fund

Mr Barry Wyatt

