



Respecting different perspectives

**11th National Paediatric
Bioethics Conference**

4-6 SEPTEMBER 2019

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 11th National Paediatric Bioethics Conference, in Melbourne.

Respect is a fundamental ethical principle – it hardly seems to need saying. But sometimes it is not easy to work out how to respect others, especially when there are differences in views and values, culture and religion, background experiences and expectations. These challenges can arise in interactions between health professionals and families, within treating teams and beyond.

What does respect mean in the many different relationships we have? Are there any limits? The ethical implications of respecting different perspectives in paediatric health care will be explored in this conference, which promises to be as engaging and thought-provoking as ever.

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

We would like to acknowledge the generous support of our conference supporters. There have been some exciting initiatives in 2019. The establishment of the **Friends of the CBC Auxiliary**, and the launch of **Essential Ethics**, a podcast site that draws on the expertise of CBC ethicists discussing cases and issues in child and adolescent health. Special thanks goes to Dr David Kolieb, Mr Richard Comber and Professor John Massie for their work in making this all possible.

The Children's Bioethics Centre acknowledges the generous ongoing support of the RCH Foundation. We are proud to announce that in the future, the CBC will be funded by the Betty Cosgrove Endowment.

We hope you enjoy this exciting program of events.



A/Prof Jill Sewell
Retiring Clinical Director
Children's Bioethics Centre
The Royal Children's Hospital



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

Sessions

Ella Latham Auditorium

Ground floor, West Building

Morning, lunch and afternoon breaks

Ella Latham meeting room

Ground floor, West Building

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

Conference contact

Karen Fellows mobile 0438 334 378



Essential Ethics podcast

You can find Essential Ethics at the iTunes Podcast App or through RCH at www.rch.org.au/podcasts

Audience participation by 'Poll Everywhere'

Please download the free app onto your iPhone, iPad or Android phone via the link: polleverywhere.com/mobile
Or use SMS at the event

The Children's Bioethics Centre

The Children's Bioethics Centre was founded in 2008, with the aim of enabling the RCH to proactively address the ethical challenges of providing health care to children and young people in an environment of technological and social change.

The Children's Bioethics Centre has become an integral part of the hospital. Located within the hospital, its staff of ethicists and clinicians are actively involved in the daily life of the hospital, providing a well-used clinical ethics service. This service helps 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 and training program, a research program, and development of policy, guidelines and clinical procedures.

The Children's Bioethics Centre offers staff at the RCH advice and support in ethically challenging patient-care matters. A Clinical Ethics Response Group meeting can be convened within 24-48 hours of a referral, with formal documentation. This service is highly valued and frequently used by hospital staff.

The Children's Bioethics Centre has become a national leader in provision of hospital-based clinical ethics services in Australia, and its staff have established international profiles in paediatric clinical ethics. The outstanding quality of work of the Children's Bioethics Centre was internationally acknowledged 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

Left to right: A/Prof Jill Sewell, Prof Clare Delany, Prof Lynn Gillam, Prof John Massie, A/Prof Jenny Hynson, Ms Karen Fellows, Dr Merle Spriggs



International keynote speakers

WEDNESDAY 4 SEPTEMBER

Negotiating diverse cultural and religious differences in a paediatric hospital

Professor Avraham Steinberg M.D.

Jerusalem is composed of a greatly diversified population – culturally and religiously.

This is fully reflected in the Shaare Zedek Medical Center – both with staff and patients.

In this presentation, Professor Steinberg will focus on three issues:

- Introduce the Shaare Zedek Medical Center and the diversity of the Jerusalem population.
- Discuss the influence of the multi-cultural and religious population on some of the daily activities in the medical center – ethical and religious examples.
- Discuss the influence of the multi-cultural and religious population on some distinctive issues – genetics, end-of-life, determining the moment of death and others.

Biography

Professor Rabbi Avraham Steinberg is a Paediatric Neurologist who has worked at Shaare Zedek Medical Centre and Bikkur Cholim Hospital in Jerusalem. He established the Medical Ethics Center of the Hebrew University-Hadassah Medical School, and served as its Director.

Professor Steinberg is the Co-Chairman of the Israeli National Council on Bioethics. He is leading authority on Jewish medical ethics, and author of the Encyclopedia of Jewish Medical Ethics.

Professor Steinberg has chaired several national committees on bioethical issues, including the Israeli National Committee for evaluation of living organ donors, the National Advisory Committee to the Minister of Health for enacting a law concerning the terminally-ill, the National Ethics Committee in accordance with the Dying Patient Act – 2005, the National Advisory Committee for amendments of the Anatomy and Pathology Act, and the National Forum concerning organ donations in Israel. He has also served as member in a variety of national and public committees.



THURSDAY 5 SEPTEMBER

How can policy become reality in children's palliative care? A realist inquiry

Doctor Sarah Mitchell MBCHB, FRCGP, MSC PALL MED

Dr Sarah Mitchell, General Practitioner and NIHR Doctoral Research Fellow, Warwick Medical School, University of Warwick, Coventry; Macmillan GP and Clinical Lead for Children and Young People, Sheffield CCG, United Kingdom

There are significant inequalities in the provision of palliative care to children internationally. Specialist Paediatric Palliative Care services, where they are available, tend not to be resourced adequately to provide palliative care for all children who could benefit from it. This presentation will discuss findings from a study, which aimed to understand the child and family experience of healthcare, taking a realist approach.

The study involved 41 serial interviews with 10 children with life-limiting or life-threatening conditions and 21 family members and four focus groups with children's palliative care professionals.



The delivery of palliative care depends on interpersonal relationships with healthcare professionals. Respect for the family and the development of trust are key mechanisms, which lead to child and family outcomes including feeling heard and supported. Within healthcare organisations, and continuity of care and legitimisation of palliative care as an approach through leadership and role modelling, can lead to improved palliative care.

Future service models that place increased emphasis on healthcare outcomes that are most important to children and families could enable policy and practice goals in palliative care to be achieved more effectively.

Biography

Sarah is a GP and National Institute of Health Research Doctoral Research Fellow at Warwick Medical School in the UK. Her interests are paediatric and primary palliative care, medical ethics, and patient and public involvement. Sarah is committed to ensuring that research has impact and, alongside clinical practice and research, has held regional and national policy roles in the UK. Currently she is a Macmillan GP in Sheffield, regional End of Life Care Co-Lead and a GP representative on national groups including the UK Association of Paediatric Palliative Medicine and the NHS England Paediatric Medicine Clinical Reference Group. Sarah tweets as @MacGPSarah.

Keynote speakers

FRIDAY 6 SEPTEMBER

Respect – an exploratory ethical dialogue

Professor Lynn Gillam BA(HONS), MA(OXON), PHD

Professor Clare Delany PHD, M HEALTH & MED LAW, M PHYSIO, B APP SC

In this discussion, Clare and Lynn will talk through some of the complexities and challenges of what seems to be a very simple ethical idea – that we should respect each other. Does respect have to be earned? Or is it due to everyone equally, regardless of who they are or what they do? Maybe we have a greater obligation as health professionals to respect patients and families than we do to respect others in our private lives. And then there is the issue of what respect for others requires us to do. We commonly talk about respecting parents' wishes, or respecting patients' autonomy. But does respect require that we always accede to what someone wants? How does respect work when there is disagreement, or aggressive behaviour? Lying behind all this is the question of what the basis of respect is, and whether there are different kinds of respect. We can show respect through actions and we can have a respectful attitude. But if you can't muster up the right attitude, is it OK to "fake it" with actions?

Biography

Lynn Gillam is a senior 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 and Global Health at the University of Melbourne.

Clare Delany is an ethicist with the Children's Bioethics Centre at The Royal Children's Hospital Melbourne. At the University of Melbourne, Clare co-ordinates the Masters of Clinical Education and is Research Higher Degree Co-ordinator in the Department of Medical Education, Melbourne Medical School.



Day 1 Wednesday 4 September

11:00am	Conference registration Ella Latham Auditorium foyer
12:15pm-12:30pm	Conference opening and welcome Ella Latham Auditorium Mr John Stanway , Chief Executive Officer, RCH Welcome to Country by Elder, Uncle Colin Hunter
12:30-1:30pm	Session 1: Grand Rounds Keynote address Ella Latham Auditorium Chair: A/Prof Matt Sabin, Executive Director Medical Services and Clinical Governance; Chief Medical Officer, RCH Negotiating diverse cultural and religious differences in a paediatric hospital Prof Avraham Steinberg , Neurologist, Director, Medical Ethics Unit and Chairman, IRB at the Shaare Zedek Medical Centre, Jerusalem, Israel
1:30-1:45pm	Break
1:45-3:00pm	Session 2: Respect and disagreement Ella Latham Auditorium Chair: Ms Jane Miller, Chief Operating Officer, RCH
1:45-2:10pm	Medical decisions for children where separated parents are not in agreement Ms Donna Cooper , Senior Lecturer, Member Australian Centre for Health Law Research, Queensland University of Technology
2:10-2:35pm	To vaccinate or not: Immunisation disputes in the Family Law system Ms Sonja Elia , Nurse Practitioner and Manager, Immunisation Service, RCH A/Prof Nigel Crawford , Consultant Paediatrician and Medical Head of Immunisation Service, RCH
2:35-3:00pm	'But that's not what she said to me...': Whose voice are we hearing? Ms Dani Gold and Ms Jennifer Burn , Senior Social Workers, RCH Family Violence Project Ms Nicola Watt , Senior Social Worker and Program Manager for Vulnerable Children and Family Violence Social Work Department, RCH
3:00-3:30pm	Afternoon break

3:30–5:15pm

Session 3: Respect *and* parents

Ella Latham Auditorium

Chair: Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre, RCH

3:30–4:25pm

Ethical considerations around parents' decisions to choose blended food for tube feeding their child

Presenters:

Dr Heather Gilbertson, Manager, Nutrition and Food Services, RCH

Ms Keryn Coster and Ms Rachael Martin, Dieticians, Nutrition and Food Services, RCH

Commentators:

Ms Bernadette O'Connor, Director Allied Health, RCH

Prof John Massie, Paediatric Respiratory Physician, Department of Respiratory Medicine and Children's Bioethics Centre, RCH; Clinical Professor, the University of Melbourne; Research Fellow, Murdoch Children's Research Institute

Moderator: Prof Lynn Gillam

4:25–4:50pm

The Twilight Zone: On the edge of the zone of parental discretion

Dr Trisha Prentice, Neonatologist, Newborn Intensive Care, RCH; Honorary Research Fellow, Murdoch Children's Research Institute; Honorary Clinical Lecturer, Department of Paediatrics, University of Melbourne

4:50–5:15pm

Should we respect parents' views about which results to return from genomic sequencing?

Dr Danya Vears, Research Fellow, Biomedical Ethics Research Group, Murdoch Children's Research Institute; Melbourne Law School, University of Melbourne

5:15pm

Conclusion

5:15–7:30pm

Welcome reception

Refreshments and canapés served

Health Education and Learning Precinct, Level 1, West Building (via Yellow lifts),
The Royal Children's Hospital Melbourne

Day 2 Thursday 5 September

7:45-8:45am

Session 4: Discussion with breakfast proudly sponsored by the Medical Staff Association
Health, Education and Learning Precinct, Level 1, RCH
Chair: A/Prof Georgie Paxton, Head Immigrant Health, Department of General Medicine, RCH

'Why don't they believe us?' Challenges with medically unexplained symptoms

Case discussion with **Dr Andrew Court**, Psychiatrist Mental Health, RCH and **A/Prof Jill Stewell**, Consultant Paediatrician, CCCH, RCH

9:00-10:15am

Session 5: Respect *and* religion and cultural values

Ella Latham Auditorium

Chair: Dr Merle Spriggs, Senior Research Fellow, Children's Bioethics Centre, RCH

9:00-9:25am

The Mature Minor, Competence, and Respect for differing beliefs

Dr Daniel Mason, General Paediatric Fellow, Department of General Medicine, RCH

9:25-9:50am

Managing family aggression and conflict in the paediatric intensive care unit: ethical challenges and proposed solutions

Dr Shreerupa Basu, Paediatric Intensive Care fellow; The Children's Hospital at Westmead, Sydney
Ms Anne Preisz, Network Manager Clinical Ethics, Sydney Children's Hospitals Network, Sydney

9:50-10:15am

Unexplored bias may undermine respect

Ms Anne Preisz, Network Manager Clinical Ethics, Sydney Children's Hospitals Network, Sydney

10:15-10.45am

Morning break

10:45-11:35am

Session 5 continued: Respect *and* religion and cultural values

Ella Latham Auditorium

Chair: A/Prof Jill Sewell, Consultant Paediatrician, Centre for Community Child Health, RCH

10:45-11:10am

Yarning with Wadja

A conversation between **Ms Selena White**, Wadja Manager, RCH; **Dr Renata Kukuruzovic**, Wadja Paediatrician, RCH; **Dr Alasdair Vance**, Wadja Psychiatrist, RCH; and **Prof Lynn Gillam**, Clinical Ethicist and Academic Director, Children's Bioethics Centre, RCH

11:10-11:35am

'May I have a female nurse, please?': Exploring the extent to which nurses can adequately provide culturally appropriate care in practice

Mr Patrick Prunster, Registered Nurse, Neonatal Intensive Care Unit and Medical Short Stay Unit, RCH

11:35am-12.30pm

Lunch break

12:30-1:30pm

Session 6: Keynote session - Respect at the end of life

Ella Latham Auditorium

Chair: A/Prof Tom Connell, Chief of Medicine, RCH

How can policy become reality in children's palliative care? A realist inquiry

Dr Sarah Mitchell, General Practitioner and NIHR Doctoral Research Fellow, Warwick Medical School, University of Warwick, Coventry; Macmillan GP and Clinical Lead for Children and Young People, Sheffield CCG, United Kingdom

1:30-1.45pm	Break
1:45-3:00pm	<p>Session 6 continued: Respect at the end of life</p> <p>Ella Latham Auditorium</p> <p>Chair: A/Prof Jenny Hynson, Head, Victorian Paediatric Palliative Care Program; Coordinator, Clinical Ethics Response Group, Children's Bioethics Centre, RCH</p>
1:45-2:10pm	<p>What does it mean respecting a child at the end of life: A Bioethics point of view</p> <p>Ms Stefania Langhi, PhD student, University of Milan, Italy</p>
2:10-2:35pm	<p>What is the value of a 'peaceful' death? And to whom is this valuable?</p> <p>Mr James Cameron, PhD student, Melbourne Law School, The University of Melbourne</p>
2:35-3:00pm	<p>Respecting families' cultural and religious beliefs and practices – going too far or not going far enough?</p> <p>Dr Sid Vemuri, Consultant in Paediatric Palliative Medicine, Victorian Paediatric Palliative Care Program, RCH</p> <p>Dr Bennett Sheridan, Paediatric Cardiologist – Ventricular Assist Devices Cardiac Intensive Care Specialist, RCH; Clinical Senior Fellow, The University of Melbourne; Research Associate, Murdoch Children's Research Institute</p>
3:00-3:30pm	Afternoon break
3:30-5:00pm	<p>Session 7: Respect and the young person</p> <p>Ella Latham Auditorium</p> <p>Chair: Ms Filomena Ciavarella, Executive Director, Strategy, Quality and Improvement, RCH</p>
3:30-3:55pm	<p>'Doing what we have to do': Giving school immunisations to young people with disabilities</p> <p>Ms Jenny O'Neill, Nursing Research, RCH; The Department of Paediatrics, The University of Melbourne; Developmental Disability and Rehabilitation Research Group, Murdoch Children's Research Institute</p>
3:55-4:15pm	<p>Differing perspectives of RCH clinicians and their adolescent patients regarding fertility counselling in transgender health care</p> <p>Mr Timothy Lai, Medical student (MD4), Department of Medicine, Dentistry, and Health Services, The University of Melbourne</p>
4:15-4:35pm	<p>Challenges of transitional autonomy: Perspectives from critical care</p> <p>Dr Shreerupa Basu, Paediatric Intensive Care Fellow, The Children's Hospital at Westmead, Sydney Children's Hospital Network</p> <p>Dr Stephen Brancatisano, General Paediatric Registrar, The Children's Hospital at Westmead, Sydney Children's Hospital Network</p>
4:35-5:00pm	<p>Respecting the child - what does this mean in theory and in practice?</p> <p>Ms Sophie Karavaras, Ms Jessica Tascone and Ms Olivia Larkens, Child Life Therapists, Child Life Therapy, RCH</p>
5:00pm	Conclusion

Day 3 Friday 6 September

9:00-10:15am	Session 8: Respect <i>and</i> the clinician Ella Latham Auditorium Chair: Dr Melanie Jansen, Staff Specialist, Paediatric Intensive Care Unit, The Children's Hospital at Westmead; Clinical Ethicist and Lecturer, Faculty of Medicine, University of Queensland
9:00-9:25am	The Monash experience of the first two years of Schwartz Rounds: A forum to support respectful communication between hospital staff Dr Katie Moore , Paediatric Oncologist, Monash Children's Hospital, Clayton, Victoria Dr Bronwyn Sacks , Paediatric Palliative Care Physician, Victorian Paediatric Palliative Care Program (RCH and Monash Children's); Chief Medical Officer, Very Special Kids Hospice
9:25-9:50am	Understanding the Unimaginable – the stories we tell to help us work with cases of suspected child abuse Mrs Shanti Petronzio and Ms Jessica Windridge , Senior Social Workers, Social Work Department, RCH
9:50-10:15am	Caring for individuals who are intersex/ have a difference of sex development, and their families Ms Chloe Hanna , DSD Clinical Coordinator, Department of Paediatric & Adolescent Gynaecology and Endocrinology, RCH
10:15-10:45am	Morning break
10:45-11:30am	Session 9: Respect <i>and</i> new technologies Ella Latham Auditorium Chair: Prof John Massie, Paediatric Respiratory Physician, Department of Respiratory Medicine, RCH; Clinical Associate Professor, the University of Melbourne; Research Fellow, Murdoch Children's Research Institute
10:45-11:05am	Germline gene editing, reasonable precaution, and the limits of parental autonomy Dr Julian Koplin , Biomedical Ethics Research Group, Murdoch Children's Research Institute; Melbourne Law School, University of Melbourne
11:05-11:30am	Going Home. Understanding the value of home in the management of children requiring long-term mechanical ventilation from the perspective of healthcare professionals Ms Juliette Jeffreys , Final Year Medical Student, University of Melbourne; Department of Respiratory and Sleep Medicine, RCH
11:30am-12:30pm	Lunch break
12:30-1:30pm	Session 10: Keynote session Ella Latham Auditorium Chair: Dr Giuliana Antolovich, Consultant Paediatrician, Neurodevelopment and Disability, RCH; Honorary Fellow, Murdoch Children's Research Institute
12:30-1:10pm	Respect – an exploratory ethical dialogue Prof Lynn Gillam , Clinical Ethicist and Academic Director, Children's Bioethics Centre, RCH Prof Clare Delany , Clinical Ethicist, Children's Bioethics Centre, RCH
1:10-1:30pm	Conference reflections Dr Melanie Jansen , Staff Specialist, Paediatric Intensive Care Unit, The Children's Hospital at Westmead; Clinical Ethicist and Lecturer, Faculty of Medicine, University of Queensland

The Friends of the CBC Auxiliary wish to acknowledge and thank the following companies for their ongoing support:

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