



The Royal
Children's
Hospital
Melbourne

21 – 23 AUGUST 2013

5th National Paediatric Bioethics Conference

Who's listening to me? Who's speaking for me?

The Children's

Excellence in
clinical care,
research and
education



Murdoch
Childrens
Research
Institute



5th National Paediatric Bioethics Conference

Who's listening to me? Who's speaking for me?

Bioethics Conference Program

Wednesday 21 August, 12.30pm - 7.15pm

Thursday 22 August, 9.00am - 5.00pm

Friday 23 August, 9.00am - 3.20pm

The Royal Children's Hospital (RCH)

50 Flemington Road, Parkville

Telephone (03) 9345 5522

- Ella Latham Auditorium
Enter via Ground Floor, RCH
- Vernon Collins Lecture Theatre
Health, Education and Learning Precinct
Level 1, West Building (via Yellow lifts), RCH

The Annual Ethics Public Forum

'The patient's voice in paediatric health care
- how much notice should we take?'

Wednesday 21 August

5.15pm drinks and canapés at Zinc Cafeteria

(Ground Floor, RCH)

6.00pm - 7.15pm Ella Latham Auditorium

Registration is open at 11.00am on Day 1 and from
8.30am each day on the Ground Floor, West Building,
RCH, outside the Ella Latham Auditorium (next to
Sandrock Café)

Morning tea, afternoon tea and lunch will be served
each day in the Health, Education and Learning Precinct,
Level 1, West Building (via Yellow lifts), RCH



Welcome

Dear colleagues,

On behalf of the Children's Bioethics Centre at The Royal Children's Hospital, it is with great pleasure that we welcome you to the 5th National Paediatric Bioethics Conference, in Melbourne.

The theme for this year's conference, "Who's listening to me? Who's speaking for me?" will address the difficulties parents and health care providers face when providing health care to children. It will look closely at issues around communication, decision making and providing information at age appropriate level.

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

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

We hope you enjoy this year's conference.



Dr Hugo Gold

Clinical Associate Professor
Clinical Director, Children's Bioethics Centre
The Royal Children's Hospital



Dr Catherine Lees

Chair, Conference Organising Committee
Business Director, Children's Bioethics Centre
The Royal Children's Hospital



The Children's Bioethics Centre

The Children's Bioethics Centre (CBC) was established in 2008, and is one of the leading paediatric bioethics centres in the world. The Centre was awarded the Hans Joachim Schwager Award for excellence in clinical ethics at the 9th International Conference on Clinical Ethics Consultation in Munich, in March this year. This inaugural award recognises innovation and pioneering work in clinical ethics.

The CBC is committed to improving children's lives by assisting clinicians to make ethical decisions and promoting the rights and responsibilities of children and their families in health care.

The Children's Bioethics Centre aims to:

- Advocate** for excellence in patient and family-centred care
- Educate** health care professionals in ethical issues
- Support** ethical best practice in children's health care
- Conduct** world-class research
- Lead** the development of a paediatric ethics agenda in health care both nationally and internationally

The CBC brings together the previous activities of the hospital's clinical ethics service with the addition of greatly enhanced education, liaison, research, and guideline and clinical procedure development. Based at The Royal Children's Hospital (RCH) Melbourne, the CBC is an initiative of the RCH in partnership with the Murdoch Childrens Research Institute (MCRI) and the University of Melbourne. It is funded by The Royal Children's Hospital Foundation, and supported by the Bioethics Development Board chaired by Mr Barry Novy OAM.

For more information visit www.rch.org.au/bioethics

The Bioethics Team

Back row: (left to right) A/Prof Clare Delany, A/Prof Lynn Gillam, Sam McQueen, Dr Jenny Hynson, Danya Vears
Front row: (left to right) Karen Fellows, Dr Catherine Lees, Dr Hugo Gold, Lauren Notini. Absent: Georgina Hall



Bioethics Conference Program

Who's listening to me? Who's speaking for me?

Day 1

WEDNESDAY 21 AUGUST 2013 12.30PM - 7.15PM

ELLA LATHAM AUDITORIUM, THE ROYAL CHILDREN'S HOSPITAL MELBOURNE

11.00am Registration Ground Floor, Entrance to Ella Latham Auditorium, RCH

Session 1 Ground rounds. Communication: The cornerstone of ethics in clinical practice

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

12.30pm *Welcome* **Dr Hugo Gold**
Clinical Associate Professor, Clinical Director, Children's Bioethics Centre, RCH

12.35-1.30pm *The impact of telling: disclosure of child abuse and lessons for communicating difficult information to parents* **Prof David Pelcovitz**
Professor Straus Chair in Psychology and Education, Azrieli Graduate School; Yeshiva University, New York

1.30pm Break

Session 2 Communicating in difficult situations: Challenges for clinicians and families

Chair: A/Prof Warwick Butt, Medical Director, Paediatric Intensive Care Unit, RCH

Communicating with families **Dr Jonathan Gillis**
National Medical Director, Organ and Tissue Authority; Clinical Associate Professor, University of Sydney; Visiting Scholar, Plunkett Centre for Ethics, St Vincent's Hospital, Sydney

1.45-3.00pm *One little boy, One brave decision, Three lives saved... Ethan James 'Jimmy' Seccull - Our story* **Jon and Michelle Seccull**
Donor parents

Communication within teams: A one-way street or a roundabout? **Judith Sloan**
Manager Social Work, Aboriginal Health and Pastoral Care Services, RCH

3.00pm Afternoon Tea

Session 3 Disability and decision-making

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

What is the ethical significance of cognitive disability for treatment withdrawal decisions? Is 'intelligism' justified? **A/Prof Dominic Wilkinson**
Associate Professor of Neonatal Medicine and Bioethics and Consultant Neonatologist at the Women's and Children's Hospital, Adelaide

3.30-5.00pm *Talking about disability in the context of pre and postnatal genetic testing* **Dr Jan Hodgson**
Senior Lecturer, The University of Melbourne and Genetics Education and Health Research, Genetic Disorders, MCRI
Kirsten Deane
Parent and Deputy Chair of the National People with Disabilities and Carer Council

Different, but not less? **Dr Giuliana Antolovich**
Consultant Paediatrician, Developmental Medicine, RCH and Department of General Medicine, Honorary Fellow, MCRI

5.00pm Conclusion

The Annual Ethics Public Forum

WEDNESDAY 21 AUGUST 2013 5.15PM – 7.15PM
 ELLA LATHAM AUDITORIUM AND ZINC CAFÉ, THE ROYAL CHILDREN'S HOSPITAL

5.15pm Welcome reception Refreshments and canapés served in Zinc Café

The Annual Ethics Public Forum

6.00pm Welcome
Dr Hugo Gold
 Clinical Director, Children's Bioethics Centre, RCH

6.10pm **The patient's voice in paediatric health care - how much notice should we take?**
 Moderated by **A/Prof Lynn Gillam** (Children's Bioethics Centre, RCH)
 RCH staff value good communication, and put considerable effort into communicating well with children and adolescents. Sometimes this communication throws up ethical challenges:

- How much weight to put on a child's negative views about treatment?
- How far to push the adolescent who does not want to communicate?
- How to manage disclosures made in confidence?

These matters are often discussed within the hospital – but what does the broader community expect and think? How 'should' these situations be handled?

This interactive forum will encourage exchange of views between health professionals and members of the community. A panel of community members will comment on case scenarios, and then the floor will be open for all to have their say. Expect a lively discussion, and some perspectives that you haven't heard before!

7.10pm **Mr Barry Novy OAM**
 Chair, Children's Bioethics Centre Development Board

7.15pm Conclusion

Bioethics Conference Program

Who's listening to me? Who's speaking for me?

Day 2

THURSDAY 22 AUGUST 2013 9.00AM – 5.00PM
 ELLA LATHAM AUDITORIUM, THE ROYAL CHILDREN'S HOSPITAL MELBOURNE

8.30am Registration Ground Floor, Entrance to Ella Latham Auditorium, RCH

Session 4 Adolescents and hard decisions in Oncology

Chair: **Dr Francoise Mechinaud**, Director Children's Cancer Centre, RCH

Communication in adolescent cancer care: Ethical imperatives, ethical challenges

Dr Angela Alessandri
 Paediatric Clinical Haematologist/Oncologist and Clinical Ethicist, Princess Margaret Hospital for Children, WA

9.00-10.30am

Who says 'enough is enough'?

Dr Helen Irving
 Senior Specialist, Paediatric Haematology and Oncology, Royal Children's Hospital Brisbane QLD

'He doesn't know he had cancer': experiences in cancer follow-up care

Susan Skinner
 Senior Nurse Coordinator, Long Term Follow Up Program, Paediatric Integrated Cancer Service (PICS), RCH

10.30am Morning tea

Session 5 Concurrent Sessions

Session 5A: Ethics and parenting

Chair: **Liat Harrower**
 RCH Family Advisory Committee
Ella Latham Auditorium

Session 5B: Decision-making in life-threatening situations

Chair: **Sue Selwyn**
 Bioethics Development Board
Vernon Collins Lecture Theatre

11.00am -11.25am

Are all parents' definitions of 'being a good parent' equally worthy of clinicians' respect?

Dr Rosalind McDougall
 Children's Bioethics Centre, RCH; Centre for Health and Society (MSPGH) University of Melbourne

What did you say? Parents' insights on communication in end-of-life decision-making

Dr Jane Sullivan
 Children's Bioethics Centre, RCH; Centre for Health and Society (MSPGH) University of Melbourne

11.25am -11.50am

Genetic carrier testing in siblings: Should we be listening to what parents want?

Danya Vears
 PhD Student, Centre for Health and Society (MSPGH) University of Melbourne; Children's Bioethics Centre, RCH

Balancing obligations: Should written information for parents about end of life decisions be strictly neutral?

Dr Vicki Xafis
 Post Doctoral Researcher, Perinatal Ethics Unit, Department of Obstetrics and Gynaecology, University of Adelaide

11.50am -12.15pm

Analysing Victoria's 'Parenting Police': What constitutes a 'good enough parent' for Assisted Reproductive Treatment (ART) access?

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

Ethical considerations with the management of Congenital Central Hypoventilation Syndrome (CCHS)

A/Prof John Massie
 Department of Respiratory Medicine, RCH

12.15pm Lunch

Bioethics Conference Program

Who's listening to me? Who's speaking for me?

Day 3

THURSDAY 22 AUGUST 2013 9.00AM – 5.00PM
ELLA LATHAM AUDITORIUM, THE ROYAL CHILDREN'S HOSPITAL MELBOURNE

Session 6 Concurrent Sessions

Session 6A Communicating in difficult circumstances Chair: Dr Rod Hunt Director, Newborn Intensive Care, RCH Ella Latham Auditorium		Session 6B Ethics and Junior Doctors Chair: Dr Hugo Gold Clinical Director, Children's Bioethics Centre, RCH Vernon Collins Lecture Theatre	
1.15-1.40pm	<i>Ethical considerations arising from the foetal diagnosis of complex congenital heart disease</i> Prof Samuel Menahem Emeritus Director, Fetal Cardiac Unit, Monash Medical Centre, Melbourne	Acting the part Dr Suzi Riess Paediatric Registrar, RCH	
1.40-2.05pm	<i>The value of listening while the patient enters: access as cultural act</i> A/Prof Jolyon Grimwade Cairnmillar Institute	<i>Ethics, education and experience: empowering junior doctors to participate in discussions about organ donation in paediatrics</i> Dr Andrew Martin and Dr Dominique Martin Centre for Health and Society, University of Melbourne	

Session 7 Improving communication

Chair: A/Prof Clare Delany, Children's Bioethics Centre, RCH

2.10-2.35pm	<i>Patients and families as partners in improving communication across the patient journey – a narrative of current work in progress at The Royal Children's Hospital</i> Stephen Ratcliffe Strategy and Improvement, RCH
2.35-3.00pm	<i>Communication, understanding and informed consent in Newborn Hearing Screening: using case studies from everyday practice to inform ethical guidelines</i> Felicity Hood Senior Project Officer, Victorian Infant Hearing Screening Program, RCH
3.00-3.10pm	Discussion
3.10-3.30pm	Afternoon tea

Session 8 'Hear Me' Play

The Australian Institute for Patient and Family Centred Care
Chair: Katherine Lorenz, Executive Director, Legal Services, RCH

3.30-5.00pm	<i>'Hear Me' is a HealthPlay written by playwright Alan Hopgood in collaboration with the Australian Institute for Patient and Family Centred Care and the Centre for Health Communication at UTS Sydney. The play focuses on the importance of patient and family involvement and empowerment as partners in their own health care, and is designed to bring arts and health together to improve communication, patient safety and quality of care across the healthcare sector.</i> Facilitated by A/Prof Lynn Gillam and Meredith Allen
5.00pm	Conclusion

FRIDAY 23 AUGUST 2013 9.00AM – 3.20PM
ELLA LATHAM AUDITORIUM, THE ROYAL CHILDREN'S HOSPITAL MELBOURNE

8.30am Registration Ground Floor, Entrance to Ella Latham Auditorium, RCH

Session 9 Engaging with families

Chair: A/Prof John Massie, Respiratory Physician, RCH

<i>Respecting family decision-making</i> Dr Andrew Watkins Clinical Director Paediatrics at Mercy Hospital for Women; Consultant Neonatologist RCH	
9.00-10.30am	<i>The consumer representative in health: Bridging the gap and creating partnerships</i> Helen Fernando Consumer Representative from Flinders Medical Centre
<i>14-Up: The impact of my brother Mitchell's life and death: How what it means to me now was shaped by what it meant to me then</i> Taylor Harrower	
10.30am	Morning tea

Session 10 Concurrent Sessions

Session 10A Parents' reasoning Chair: Dr Rosalind McDougall Children's Bioethics Centre, RCH Ella Latham Auditorium		Session 10B Communication with adolescents Chair: Dr Michelle Telfer Clinical Lead Adolescent Medicine, Centre for Adolescent Health, RCH Vernon Collins Lecture Theatre	
11.00am-11.25am	<i>When parents hold false beliefs: Understanding the existence and implications of therapeutic misconceptions in first-inhuman and early phase phase research involving children</i> Nikola Stepanov Centre for Health and Society (MSPGH) and Rural Health Academic Centre (MMS), University of Melbourne	<i>"It's not just a leg they're treating, it's a leg attached to a young person". Do all adolescents attending hospital require a full psychosocial assessment?</i> Dr Rony Duncan Senior Research Fellow, Centre for Adolescent Health, Population Health, MCRI; Department of Paediatrics, University of Melbourne	
11.25am-11.50am	<i>Do parents' reasons for wanting their child to undergo facial surgery impact on the ethical acceptability of these surgeries?</i> Lauren Notini PhD Student, Centre for Health and Society (MSPGH) and Department of Paediatrics, University of Melbourne; Children's Bioethics Centre, RCH	<i>"We lost her for a little bit". A qualitative study of siblings in treatment of Anorexia Nervosa</i> Tanja van Langenberg Provisional Psychologist, Doctor of Clinical Psychology Candidate, School of Psychology and Psychiatry, Monash University, Melbourne	
11.50am-12.15pm	<i>"You never told me!" An adolescent case presentation</i> A/Prof Jill Sewell Deputy Director, Centre for Community Child Health, RCH Facilitated by A/Prof Lynn Gillam	<i>Group supervision as a teaching tool</i> Prof John Rogers AM Emeritus Senior Medical Geneticist, Victorian Clinical Genetics Service and RCH	
12.15-1.15pm	Lunch		

Notes

FRIDAY 23 AUGUST 2013 9.00AM – 3.15PM
ELLA LATHAM AUDITORIUM, THE ROYAL CHILDREN'S HOSPITAL MELBOURNE

Session 11 Altering children: Who should we listen to?

Chair: Prof Paul Monagle, Stevenson Professor and Assistant Dean, RCH Academic Centre, University of Melbourne; Paediatric Haematologist, RCH

1.15-1.30pm *When ethics hits the wall: Controversial treatments which alter children*
A/Prof Lynn Gillam
Academic Director and Clinical Ethicist, Children's Bioethics Centre, RCH; Centre for Health and Society (MSPGH), University of Melbourne

1.30-1.40pm *"The Ashley treatment"*
Dr Merle Spriggs
Children's Bioethics Centre, RCH; Centre for Health and Society, University of Melbourne; Murdoch Childrens Research Institute

1.40-2.00pm *Parental reasoning regarding controversial treatment for their child: A case study*
Dr Nikki Kerruish
Department of Women's and Children's Health and Bioethics Centre, University of Otago, Dunedin, New Zealand

2.00-2.15pm Discussion

The telehealth debate: "Is telehealth video-consultation ethical?"

Chair: Susan Jury
Telehealth Program Manager, RCH

PANEL MEMBERS

FOR:

Helen Jowett
Trauma Service Manager and Nurse, RCH

John Stanway
Executive Director, Executive Services, RCH

2.15-3.15pm
Dr Jenny Hynson
Paediatrician, Medical Director, Victorian Paediatric Palliative Care Program, RCH

AGAINST:

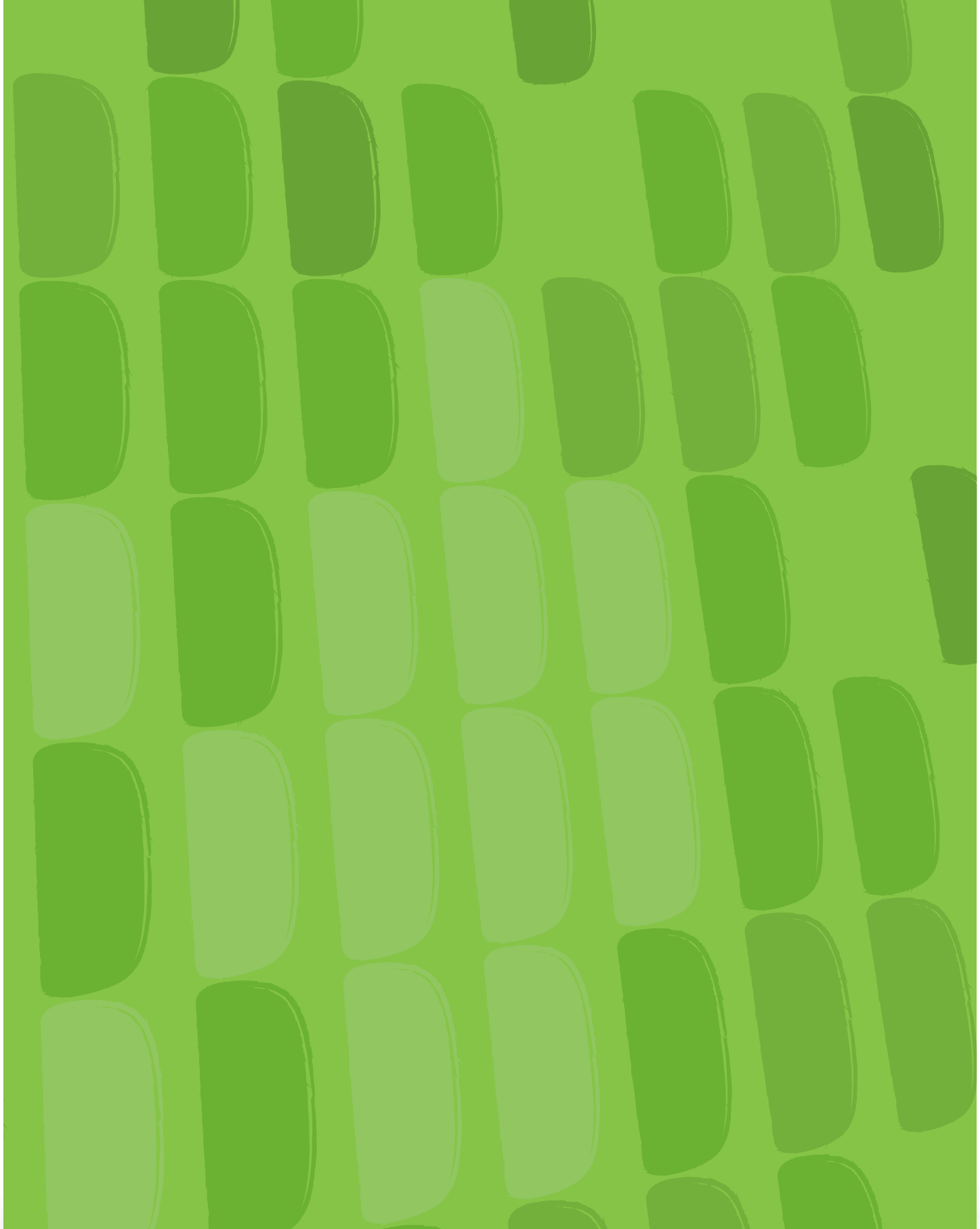
John Vernon
Manager Adolescent Medicine, Centre for Adolescent Health, RCH

Prof Yves Heloury
Professor of Paediatric Urology, RCH

A/Prof Andrew Kornberg
Director and Paediatric Neurologist, Department of Neurology, RCH

3.15pm Close
Dr Hugo Gold

3.20pm Conference Conclusion



Sponsored by Mira and David Kolieb and family

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