



Children's Bioethics Centre

Annual Report 2023



The Royal Children's Hospital



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1. From the Directors

Clinical Activities

The last 12 months have continued the trend that we have been seeing in the clinical work of the Children's Bioethics Centre (CBC). The cases continue to be more complicated, far more than when the service started 15 years ago. This seems to be a combination of technological capability resulting in increasing survival of children who would previously have died and social pressures, partly that survival of children with disabilities is more commonly accepted, and at times expected. The other societal pressure may be a lower acceptance of, or respect for, medical opinion. This means that some of the cases are more drawn out from a clinical perspective and the ethical issues take much longer to resolve.

The complexity of cases has given us the opportunity to consider the processes we follow with ethics consultation. The CBC has increasingly supported medical teams through attendance at multidisciplinary team (MDT) meetings. MDTs are used to discuss complex patients within a team, but traditionally have not involved medical ethics support. It can be hard to find times to bring relevant team members together, so CBC involvement is both practical and gives the opportunity to integrate ethical discourse in team meetings.

During 2023, CBC staff have met with a number of parents to listen to their perspective and support them with complex medical decision-making. This is in line with the processes of many international clinical ethics groups that seek to gain the authentic voice of the parents and support decision-making, in conjunction with the work of supporting the clinical decision-makers as we have always done. All parties to these complex issues, that is the parents (and children), clinical teams and clinical ethics service have found this helpful, and we will continue to offer this service.

The other clinical development of 2023 has been the introduction of ethics debrief sessions, in response to a growing need to support staff after a difficult patient journey. In most cases, these have been held after a patient has died and in conjunction with palliative care staff and psychologist support. Requests for these sessions grew from recognition of the value of ethical discussion during the complex patient journey and reflection afterwards.

Clinical Ethics Response Group Training

We have been working hard to upskill our Clinical Ethics Response Group (CERG) members with dedicated CERG education sessions in order to develop their capacity to contribute to better discussions and deliver better opinions for referred cases. These education sessions have been well received and CERG members report positive feelings of engagement with the CBC and professional enrichment. The sessions have included discussions of the "Seven Steps" that we have identified as occurring in CERGs (see Section 4 in this report) and simulated CERG sessions with different members taking the lead as Chair.

Staff

During 2023 we welcomed Sharon Feldman to the team, initially as backfill for Professor Clare Delany's long service leave and now employed on-going as a clinical ethicist.

Professor Clare Delany made the difficult decision to resign from the CBC after 15 years of service. Clare was with the CBC from its inception and the remarkable growth of the CBC is in no small part due to her expertise and hard work. We wish Clare well as she continues her University of Melbourne work and other opportunities in Clinical Ethics.

Ethics support for ward nurses

Dr Jenny O'Neill, CNC bioethics, has continued to lead the program of ward support for nurses. These sessions are popular on the wards we attend, and we will be looking to expand this program in 2024. The sessions serve several purposes: ethics education, ethics support for cases on the ward and ethics debrief. The sessions are developing the clinical ethics capacity of the nursing staff and familiarity with the CBC service. A number of ethics referrals have arisen from these sessions.

Conference

We hosted the 14th National Paediatric Bioethics Conference in the first week of September. The theme was the Ethics of Innovation. A more detailed summary appears later in the Annual Report. The in-person format returned after 3 years of online conferences and participants revelled in the interactive nature of the conference. Thank you to our CBC staff for bringing the conference together and thank you to our financial supporters, The Friends of the CBC and the Humanity Foundation.

Education and Capacity Building

The CBC education program (CERG education, monthly Bioethics Forum, podcasts and annual conference program) continues at full tilt thanks to the enthusiasm of Dr Georgina Hall. Georgina is also leading some of the RCH clinical team education sessions, supporting the CBC advice to clinicians in CERGs and finding evidence-based literature to augment the advice we provide. In addition to the annual conference, the CBC also co-hosted a one-day symposium on Procedural Holding, in collaboration with Nursing Research. A more detailed report is included later in this Annual Report, but the symposium highlighted the ethical complexities of procedural holding, which is a not uncommon practice for children having procedures at RCH. Under the leadership of Dr Jenny O'Neill, Bioethics CNC, we ran the Ethics in Clinical Practice (ECP) course again in 2023. This year, we welcomed Allied Health staff to the program, in addition to nursing staff. The course was well received and will contribute significantly to building ethics capacity at RCH. The program will continue in 2024.

Visitors

One of the exciting aspects of working in the CBC is the interactions we have with our visitors and the ideas from outside that they bring. It is a testament to the reputation of the CBC that we have a solid stream of requests to spend time with us, locally, nationally and internationally. Within RCH, we have had senior medical staff join us on sabbatical leave which helps develop capacity in bioethics within medical teams. We additionally host interns from the Monash Masters of Bioethics program, who complete a semester with the

CBC and make valuable contributions to the lifeblood of the centre. All visitors contribute to the CBC with research, presentations at our monthly forum and journal publications.

Research

While clinical advice and support for RCH staff, along with capacity building through education, are the main focus of the CBC, there is no doubt that research is an important endeavour for us. Research questions are derived from our clinical experiences and help us develop a deep understanding of the work that we do. This is both exploring ethical situations, but also exploring how clinical ethics is done. Clinical ethics is an evolving field and the work of the CBC is contributing to the understanding of how clinical ethics can be done better and how it can help our patients, their families and our staff. The published papers listed in the Annual Report capture the diversity of our work and contribution to the field. Much of this work is done after the clinical work and education work have been completed, in the own time of the staff. Congratulations to all on seeing so much work through to publication!

Book

The CBC's second book, *Deciding with Children*, has an international publisher - Elsevier. A number of leading bioethicists, clinical ethicists and clinicians from The Royal Children's Hospital as well as nationally and internationally have agreed to be part of this exciting project. We are aiming for completion by late 2024.



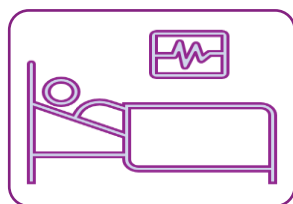
Professor John Massie
Clinical Director



Professor Lynn Gillam
Academic Director

2. The work of the Children's Bioethics Centre

The Children's Bioethics Centre is a department of the Royal Children's Hospital, within the Division of Medical Services. It is funded primarily by The Royal Children's Hospital Foundation. The CBC works across all areas of the hospital, to provide clinical and organisational ethics support in a variety of ways. Our work falls into four domains, as shown below, all connected with each other. The frontline activities of the clinical ethics service are founded on and feed into our academic research.



Clinical Ethics Service

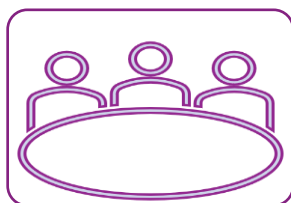
One-on-one advice

Ethics advice in Multidisciplinary meetings

Clinical Ethics Response Group (CERG)

Family ethics consultation

Ethics debrief with staff



Capacity Building through Ethics education

Ethics education sessions for clinical teams and departments

Attendance at ward meetings

Annual Paediatric Bioethics Conference

Workshops

Ethics in Clinical Practice Courses

Grand Rounds

JRMO Teaching

Podcasts

eLearning

Web Resources

Hosting Interns



Policy and leadership

Policy advice to RCH Executive

Advice to clinical departments and teams on processes and procedures

Policy briefing papers

Membership of RCH Committees

Development of RCH Nurse-ethicist leadership group

Hosting Senior Medical Staff sabbatical leave



Research and publication

Academic Research

Supervision of research students:

- PhD
- Masters of Bioethics
- MD Research Projects

Peer-reviewed publications

3. The Bioethics Team



(Standing L-R): Dr Jenny O'Neill, Bioethics CNC
Dr Georgina Hall, Clinical Ethicist and Ethics
Education Co-ordinator
Ms Sharon Feldman, Clinical Ethicist

(Seated L-R): Professor John Massie, Clinical
Director, CBC
Professor Lynn Gillam, Academic Director, CBC

(Absent: Professor Clare Delany)

Professor John Massie

MBBS, FRACP, PhD, GAICD



John is the Clinical Director of The Children's Bioethics Centre and senior consultant physician in the Department of Respiratory and Sleep Medicine, RCH. He is also a Professorial Fellow, Department of Paediatrics, University of Melbourne and an Honorary Fellow, Infection and Environment, MCRI. John is a clinician ethicist and paediatric respiratory physician at the RCH. He looks after children with neuro-disability requiring ventilator support and also works in the RCH cystic fibrosis clinic. John has published a number of papers and book chapters on ethical issues relating to paediatric respiratory medicine and the medical humanities. John is the host of the CBC podcast show, Essential Ethics.

Professor Lynn Gillam AM

BA Hons, MA (Oxon), PhD



Lynn is a Senior Clinical Ethicist and has been Academic Director of the Children's Bioethics Centre since its inception in 2008. She is also Professor in Health Ethics, Department of Paediatrics, University of Melbourne. She is an experienced clinical ethicist, originally trained in philosophy (MA, 1988 Oxon) and Bioethics (PhD, Monash, 2000). Lynn has extensive experience in clinical ethics case consultation and has published widely in bioethics and paediatric clinical ethics. She also provides policy advice and leads research into a range of issues in paediatric clinical ethics –including end of life decision making, management of differences of sex development, information-giving to children, and parental refusal of treatment. Lynn's research is practically focused, combining methods of analytic philosophical bioethics and qualitative research. At the University of Melbourne, Lynn teaches ethics in the MD program and supervises graduate research students.

Professor Clare Delany

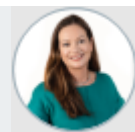
BAppSci (Physio), Masters of Physiotherapy,
Master Hlth and Med Law, PhD



Clare is a Senior Clinical Ethicist. She has been with the Children's Bioethics Centre in a clinical ethicist role for 15 years. Clare is also a Clinical Ethicist at the Peter MacCallum Cancer Centre. Clare has clinical experience as a physiotherapist and qualifications in Health and Medical Law and Medical Ethics. At the University of Melbourne, Clare is a professor of Health Professions Education Research and Practice in the Department of Medical Education, Melbourne Medical School. Clare has published widely in applied health ethics and health ethics education.

Dr Georgina Hall

BA (Joun) M. Bioeth, PhD



Georgina is a bioethicist who works as a Clinical Ethicist and is the Ethics Education Coordinator at the Children's Bioethics Centre. She trained in Bioethics (MBioeth, Monash University, PhD Bioeth University of Melbourne) and communications (BAJourn, RMIT). Georgina has been involved with the Centre since its inception in 2008 and oversees the development and delivery of a wide range of traditional and innovative education and training programs within the Centre include producing e-Learning modules, podcasts, building the Merle Spriggs Bioethics Library and developing a curated collection of bioethics resources available at the Centre. Her research interests include reproductive ethics, moral theory and shared decision making in paediatrics, and she is currently co-editing a book "Deciding with Children" with colleagues at the RCH.

Dr Jenny O'Neill

BA, BN, PGDip (Paed Nurs), MN, MBioeth, PhD



Jenny is the inaugural Clinical Nurse Consultant in Bioethics. She has worked at The Royal Children's Hospital for over 20 years. Her previous clinical experience includes a variety of paediatric nursing roles, including in emergency, surgery, medicine and adolescent health, and a total of 10 years as a Clinical Nurse Consultant in Neurodevelopment and Disability. Jenny completed a PhD in Nursing in 2020 and a Masters in Bioethics in 2021. She combines her bioethics work with her roles as a Clinical Nurse Consultant in Nursing Research and an Honorary Fellow of the University of Melbourne.

Ms Sharon Feldman

LLB, BA (Hons), MS (Bioeth)

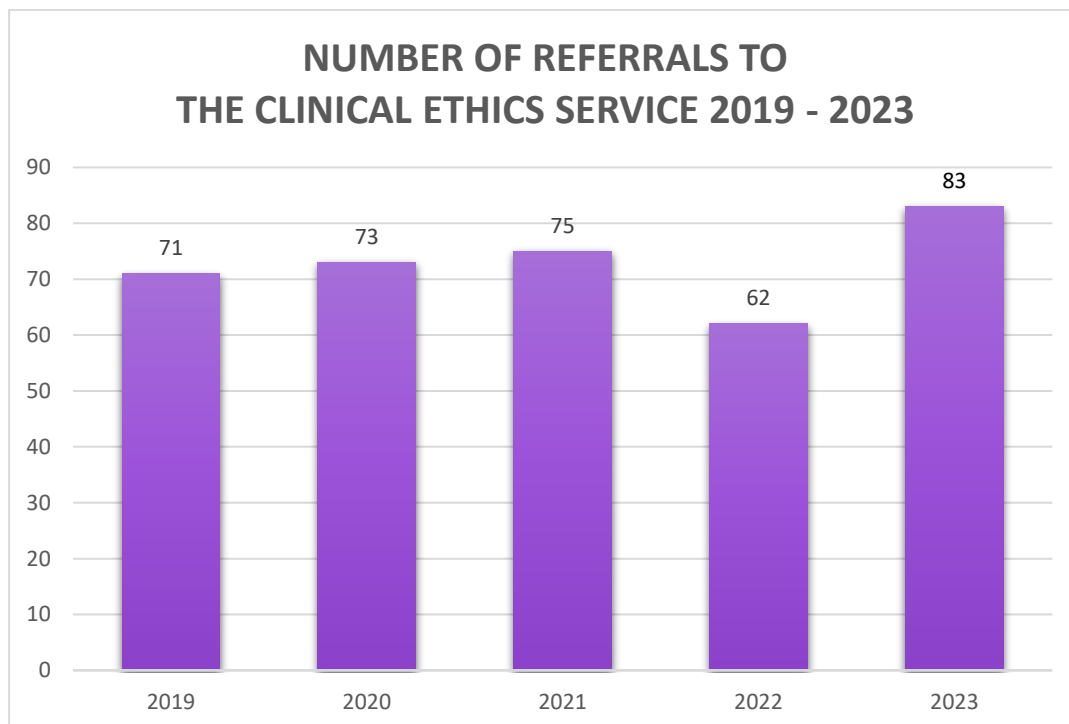


Sharon is a Clinical Ethicist at the Children's Bioethics Centre, as well as at Peter MacCallum Cancer Centre and Austin Health. Previously, Sharon worked as a healthcare lawyer, before completing a master's degree in bioethics at Columbia University and a two-year clinical ethics fellowship at the Cleveland Clinic. She is also pursuing a PhD on the practice of clinical ethics.

4. Clinical Ethics Services 2023

Referrals for ethics consultation and support services

There were 83 referrals to the Clinical Ethics Service in 2023. This is a significant increase of 40% on the number for the previous year (62), and a 20% increase on the average over the preceding 5 years (69). Part of this is due to increased numbers of referrals from the Fertility Preservation (FP) team, and the rest reflects increased demand across an increasing number of clinical departments.



Referrals can be made by Campus staff members. Staff make referrals when they identify an ethically complex or challenging situation, for which they would like the specialist assistance of the Clinical Ethics Service in thinking through and resolving. Referrals to clinical ethics are not mandated and rarely inform clinical protocol, except in relation to fertility preservation (FP).

Fertility Preservation refers to procedures that can be offered to children undergoing treatment that will or might affect their fertility in the future, such as chemotherapy for cancer. At the request of the FP clinical lead, there is a protocol for referring proposed fertility preservation procedures for pre-pubertal children to the Clinical Ethics Service, because these procedures are mostly not established practice. The criteria for referring a proposed fertility preservation procedure for clinical ethics review has changed over time, as procedures for some groups of patients have become more established, with a stronger evidence base for success. In early 2023, FP procedures for pre-pubertal girls would no longer be routinely referred to clinical ethics, for this reason. Routine referrals are now only made for pre-pubertal boys. Despite this, the number of FP referrals rose from 24 in 2022 to 32 in 2023, due to increased numbers of procedures to collect testicular tissue from pre-pubertal boys.

Types of ethics consultation services provided

The Clinical Ethics Service provides different types of clinical ethics consultation, depending on what the referrer requests, and what is most suited to the ethical issue/s involved.

For staff

The types of ethics consultation provided to RCH staff are:

- **Clinical Ethics Response group meeting**
Formal clinical ethics consultation: meeting with members of the Clinical Ethics Response Group and members of the treating team, chaired by Clinical Ethicist, with full documentation.
- **Clinical ethics staff attend ward/clinic or MDT meeting re patient**
Members of the Clinical Ethics team attend a clinical, ward or unit meeting about the patient, with summary documentation.
- **Ethics debrief**
Facilitated discussion of an ethically challenging situation or event, particularly in response to staff moral distress.
- **Individual ethics consult**
Clinician meets with Clinical Ethicist – confidential and not documented.
- **Policy Advice**
Members of the Clinical Ethics team meet with RCH staff to facilitate discussion of ethical considerations, and provide comments and assistance on drafting procedures or process documents.

For families

During 2023, we also began to formally provide clinical ethics engagement with families. This can take a number of forms, including a meeting with a family prior to a CERG or ethics MDT, a family ethics consultation, and ethics mediation. The table below summarises the types of services provided in 2023.



Referring teams and departments

Referrals for clinical ethics consultation services came from a wide range of teams and departments across the hospital. These referrals related to both in-patients and outpatients, some of whom had chronic conditions, others who had acute or life-threatening conditions. The table below shows number of referrals in 2023 according to department/clinical team. (Note that this table does not include routine FP referrals)

SOURCE OF REFERRALS IN 2023			
1 referral	2 referrals	3 referrals	4+ referrals
Cardiology	Bone Marrow Transplant	Comfort Kids	Adolescent Medicine (5)
CHIPS	Endocrinology	Differences of Sex	
Cockatoo	Gastroenterology	Development team	
CPRS	General Medicine	Neurodevelopment and	
Creative studios	MCMUS	Disability	
Day Surgery	Metabolics	Paediatric Intensive Care	
Dermatology	Neurology		
Immigrant Health	Transition team		
Liver Team	Victorian Clinical Genetics		
Neonatal Intensive Care	Service		
Palliative Care			
Plastics			
Refugee Health			
Rehabilitation			
Respiratory			
Sugarglider			
VFMPs			

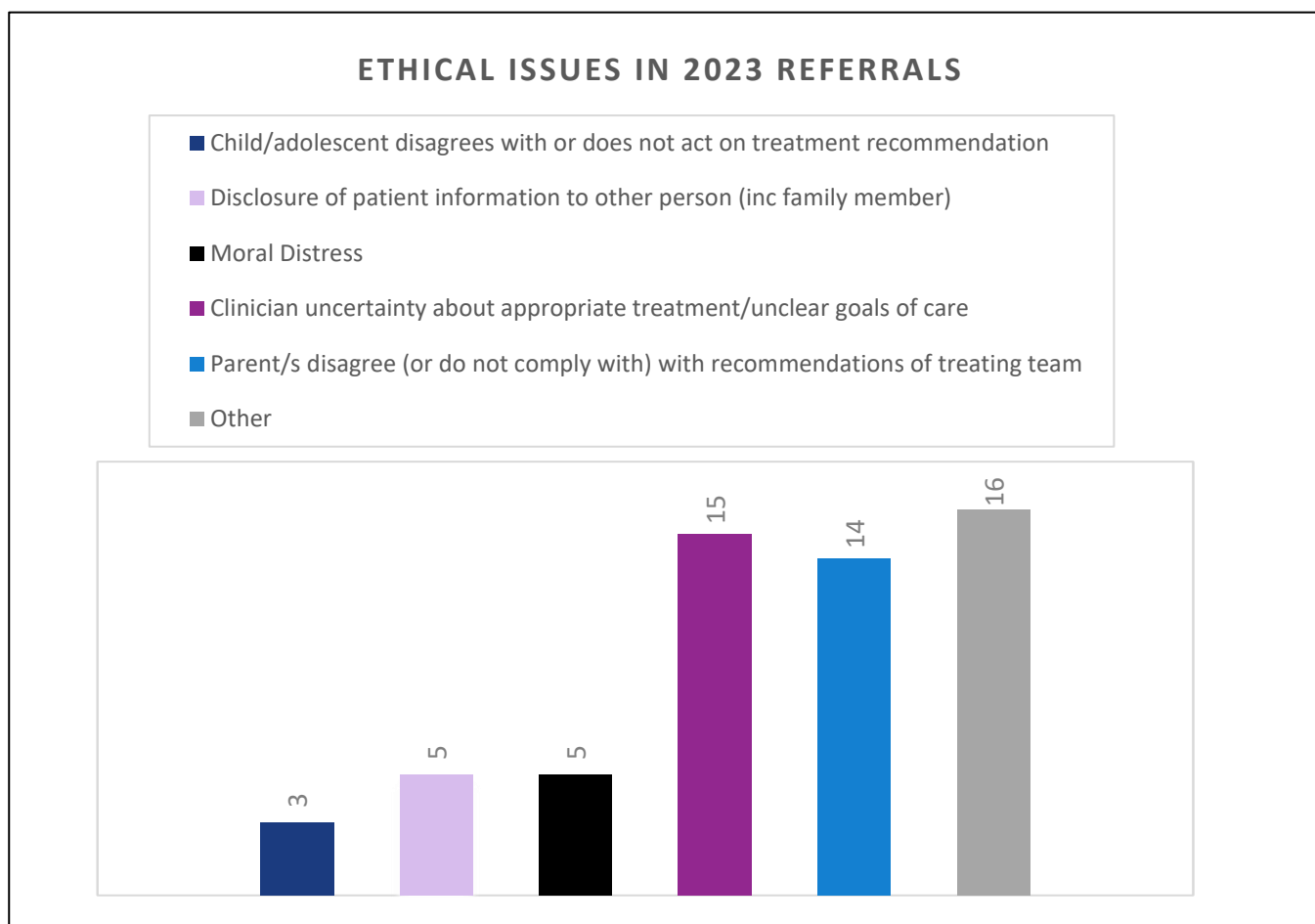
Types of ethical issues and clinical situations

The details of the referrals to the Clinical Ethics Service are confidential. However, we can provide a breakdown of the general types of clinical situations for which referrals were made, and the common ethical themes. The chart on the following page shows the types of situations and ethical challenges which prompted referrals. Some referrals in complex situations had more than one of these features.

The most common types of situations were:

- **Parent/s disagreeing with (or not acting on) recommendations of treating team.** This include situations where parents refuse medically recommended treatment for their child, or seek out forms of treatment that clinicians are not recommending, including experimental and non-evidence-based treatment.
- **Clinician uncertainty about appropriate treatment/unclear goals of care.** Clinicians often seek ethics support when they are grappling with decisions about what form of treatment would be in the best interests of the child, especially in socially complex situations, or where a palliative approach is being considered.

In some instances, the primary reason for referral was moral distress of staff. This refers to situations where staff feel significant concerns about whether they are able to do the right thing by the child. Moral distress is often a feature of situations where parents or child are not co-operating with medically recommended treatment, or where there are different views about what would be in the child's best interests, particularly when the child may be nearing the end of their life.



The category of “Other” covers a wide range of ethically challenging situations, including:

- Families reluctant to follow a plan to transition to adult services as their child approaches the age of 18.
- Use of restraint in delivering therapeutic interventions, including tube feeding in adolescents with anorexia.
- The involvement of children and adolescents in decisions about their medical treatment, including the issue of parents wanting information withheld from their child.
- Ethically appropriate management of conflict.

5. Ethics Education Program

The CBC provides a multi-faceted program of education and professional development in clinical ethics. The major aspects of this program are:

- The departmental ethics education program
- Regular departmental and ward meeting attendance
- The annual National Paediatric Bioethics Conference
- Bioethics Forum (monthly)
- Ethics in Clinical Practice (ECP) course
- Essential Ethics podcast series
- Training for Clinical Ethics Response Group members

The CBC also hosts clinicians from within and outside RCH doing a sabbatical, and students at various levels undertaking research or an ethics internship. The education program is co-ordinated and supported by Dr Georgina Hall. All CBC staff play an active role in delivering education and providing supervision and mentoring for professional development.

Departmental Ethics Education Program

The Children's Bioethics Centre conducted 92 Ethics Education sessions across a wide array of hospital departments, wards and units of the RCH in 2023. Our aim is to provide at least one education session per year for every clinical department. Some departments might request more sessions per year. These included scheduled departmental ethics education sessions, one-off and regular ward education sessions at The Royal Children's Hospital, and several campus-wide and external sessions. These included education to the following groups and departments:

Departmental Ethics Education Session (up to 4 annually):

Adolescent Medicine
Allergy & Immunology
Banksia
Child Life Therapy
Clinical Haematology
Colorectal & Pelvic Floor Reconstruction Service
Emergency Department
Gastroenterology & Clinical Nutrition
Gender Service
Kelpie
Medical Education
Neuro Development & Disability
Neurology
Nursing Education
PIPER
Possum
Transition

Regular ward education sessions (monthly/bi-monthly):

Allied Health
Butterfly/NICU ward
Cockatoo
Complex Care
Complex Care Social Work
Critical Care Social Work
PICU
Sugarglider
Wallaby
Wombat

Invited Sessions in other RCH Programs:

Career Advancement Year (nurses)
Comfort Kids workshops
ECLS (ECMO) courses
Graduate nurses
Moral distress simulation day (NICU)
Tuesdays@2 (nurses)

Most sessions were delivered onsite and in person, with some also offered on-line or hybrid, to best meet the needs of clinical staff. These sessions typically run for one hour, in the regular timeslot allocated by the department or team for education. The content of the education session is tailored to suit the needs and interests of the clinical staff in the department. The usual format is discussion focused on a case nominated and presented by clinical staff, or a recurring issue or type of ethically challenging situation experienced by staff in that clinical setting.

Bioethics Forum

The Bioethics forum is an opportunity for ethics enthusiasts to discuss and broaden their knowledge of ethics. The monthly one-hour sessions include review of journal articles, discussion of current ethical issues and presentations of work conducted by the CBC staff, students, interns and visitors.

Date	Topic
9 Mar 2023	We could do more, but should we? Approaching decisions about life-prolonging treatments for children with life-limiting conditions.
3 Apr 2023	The fraught notion of a 'good death' in paediatrics
3 May 2023	Children and bioethics: clarifying consent and assent in medical and research settings
19 Jul 2023	Sustaining Bereavement Practice in the Acute Pediatric Setting; The Ethics of Use of Self
21 Aug 2023	ChatGPT and its implications for the healthcare sector
11 Oct 2023	What's the difference if you're very small?
27 Nov 2023	Analysis of the Nuffield Council on Bioethics Report: Disagreements in the care of critically ill children
18 Dec 2023	Bioethics Christmas Ethics Debate

Bioethics Forum is open to anyone who is interested. Please contact Georgina Hall if you would like to be added to the mailing list (georgina.hall@rch.org.au)

Ethics in Clinical Practice (ECP) Program

In 2023 we continued to run our ECP Program. This is a 3-day course with the aim to increase clinician confidence and engagement in clinical ethics discussions and decision making. The overall purpose is to optimise ethical awareness at RCH.

The ECP Program covers topics such as ethical principles and frameworks, asking ethical questions, moral distress and regret, truth-telling, deciding with children and thinking about advocacy. It is run through case discussions and interactive activities using clinical scenarios. We include participants in a mock Clinical Ethics Response Group meeting and conclude the program with a simulation on Day 3 with a professional actor. Originally an ethics course for nurses, the overwhelmingly positive feedback led us to extend to Allied Health clinicians with the first 2023 course comprising 16 social workers, child life therapists, physiotherapists, occupational therapists and psychologists. Feeling bold, in the second course in 2023 we combined nursing and allied health participants which further increased the richness of discussion. A course for doctors is planned in the future.

6. The 2023 National Paediatric Bioethics Conference

This year's conference was another great success, following in the tradition of previous conferences. We were joined by 388 registrants, from RCH and beyond, and 34 speakers across 13 sessions.

We were excited to be back to an in-person conference, after a number of years of COVID-induced online-only conferences. The Ella Latham Theatre was buzzing right from outset. The engagement of the audience with the speakers and the conference topics was a joy, as was the collegial atmosphere.



The conference addressed the ethical aspects of innovation in healthcare.

Innovation takes many forms, ranging from new drugs and devices to new ways of delivering services. Innovative treatments can be delivered in a planned, staged and carefully overseen process to reach a whole patient population, or as an ad hoc change to the standard of care to meet the needs of an individual patient. Whatever form it takes, innovation in healthcare for children and young people has ethical dimensions and can be ethically challenging. Although it is generally regarded as a good thing, innovation doesn't always go well and there can be unintended consequences.

Speakers and panellists delved into the ethical challenges of a wide variety of innovative treatments and practices. Topics included:

- Paradigm shifts in orthopaedic surgery
- Artificial intelligence at RCH – the good, the bad and the ugly
- High-cost and novel therapies
- The ethics of integrating artificial intelligence into paediatric genomic medicine
- A process for random selection for clinical trial participation
- Bariatric surgery in adolescence
- Sharing decision-making for innovative therapies in critical care
- Gender-affirming care – opportunities and challenges when care is consumer-led
- Managing the unintended consequences of innovation: An EMR story

The Friends of the CBC Hypothetical was held on the Thursday evening, engaging the audience in a lively discussion of a realistic but hypothetical case involving fertility preservation for a pre-pubertal boy about to undergo cancer treatment.

International Speakers at the National Paediatric Bioethics Conference



Opening Keynote

Rethinking Innovation: A Working Ethics Framework for Paediatrics

A /Prof Bryanna Moore

Dept of Bioethics and Health Humanities
University of Texas

Advances such as vaccine technology, the development of new pharmaceuticals and data gathering and processing methods, to the completion of the human genome project, have impacted the health of generations, arguably for the better. Yet innovation raises important questions about who scientific "breakthroughs" serve and what values drive such "progress". In this presentation, A/Prof Moore explored the relationship between bioethics and innovation, and discussed the role of ethical considerations in innovation and team science. She proposed a framework for a "bioethics of innovation" in paediatric research and practice. Finally, she reflected on what doing "innovative bioethics" might entail.

Thursday Keynote

Hope, humility and innovation

Prof Ian Kerridge

Haematologist/Bone Marrow Transplant physician,
Royal Northshore Hospital
Professor of Bioethics and Medicine,
Sydney Health Ethics, University of Sydney



In this session, Professor Ian Kerridge discussed how innovative treatments including the chance for patients to be enrolled in clinical trials offers hope for patients and their families. And yet the (innovative or experimental treatment) opportunity also results in ethical challenges; including problems of therapeutic misconception on the part of patients and their families, and for clinicians and clinician/researchers, problems explaining the goals, risks and benefits of a proposed innovation.

*Our next Conference will be held 4th–6th September 2024
'The Cases We Carry: Navigating Ethical Complexity in Paediatrics'*

7. Procedural Holding Symposium

Another major event on the CBC calendar this year was the Procedural Holding Symposium, initiated by our Bioethics CNC, Dr Jenny O'Neill. This symposium was a collaboration between Nursing Research and CBC, and was held on Wednesday 29th November 2023. It aimed to bring acute care and community paediatric clinicians, together with interested academics, researchers, and ethicists to hear from a diverse group of presenters and discuss the ethical and logistical issues surrounding holding children for procedures.



The Keynote Speaker was Prof Lucy Bray, Edge Hill University, UK.

Lucy Bray leads the international iSupport group on rights-based standards on procedural holding.

Her presentation of the issues in procedural management in paediatrics from a child rights lens generated much discussion.

There was an exciting program of 12 oral presentations and 3 panel session with a mixture of research, case studies and reflections.



Overall we had 380 registrations for this day from across all states of Australia and New Zealand from a variety of backgrounds. This reflects the growing awareness of the importance of minimising psychological harms for children during routine healthcare. Following the symposium, we ran a Research Collaboration workshop on the morning of Thursday 30th November with attendees from the symposium. We are in the process of exploring collaboration opportunities and developing some focus areas moving forward.

8. Essential Ethics Podcast

The Essential Ethics podcast from the Children's Bioethics Centre presents discussion of challenging cases that come up when treating children. After a decade or more of experience our team of world-recognised ethicists takes on the hardest cases and ethical concepts. Essential Ethics is informative, interesting and always relevant to contemporary paediatric health care issues. The podcast is hosted by Professor John Massie with the support of the CBC team and clinicians of The Royal Children's Hospital.



In 2023 the number of downloads of the Essential Ethics podcast was up 57%, with a total of 8,207 downloads on podcast platforms from Feb 2023 -February 2024.

New Series of Essential Ethics in 2023

Highlights of 13th National Paediatric Bioethics Conference 2022

- Friends of the CBC hypothetical
- Abandoned or relinquished? Challenges for hospital staff
- Vaccinating young people against parental wishes
- Addressing conflict: An introduction to empathic curiosity

Series on Deciding with children:

- The voices of experience: the ethics of partnering with families in paediatric research
- Determining capacity to decide and refuse
- Is deciding with children a human right?
- Finding my voice
- Beyond disability
- Parents vs clinicians: a path to resolution

9. Policy and Leadership

The Children's Bioethics Centre provides ethics support for the RCH Executive and senior clinical staff on matters relating to hospital, department and clinical teams, policies, processes and procedures.

Support to RCH Executive

- Advice to the Executive Director of Medical Services on treatment not previously used in children
- Membership of the RCH Drug Usage Committee (Prof John Massie)
- Membership of the New Technologies Committee (Prof John Massie)

Support to RCH senior clinicians

Prof Lynn Gillam provides embedded ethics support for senior clinicians leading clinical teams in three ethically complex and potentially contentious areas:

- Fertility Preservation
- Differences in Sex Development
- Management of Complex Medically Unexplained Symptoms

Advice on specific issues

- Laser hair removal - eligibility criteria for patients, and enhanced information for new patients
 - *Professor Lynn Gillam and Dr Jenny O'Neill*
- Vaping in the peri-operative period – what information and advice should be given to adolescents?
 - *Professor Lynn Gillam and Dr Jenny O'Neill*
- Consumer-initiated request for help in publicising their family's health situation
 - *Professor Lynn Gillam, Dr Georgina Hall and Dr Jenny O'Neill*
- Articulating ethical best practice for RCH use of patient images and patient stories
 - *Dr Georgina Hall and Professor Lynn Gillam*

10. Nursing ethics program

The CBC Nursing ethics program is led by Dr Jenny O'Neill, now in her third year with the CBC as Clinical Nurse Consultant in Bioethics. The program continues to grow, with general and targeted ethics support for nurses in 2023, as well as opportunities for RCH nurses in clinical ethics professional development and leadership on the RCH Campus. The nursing ethics program is closely integrated into the work of the CBC, strengthening and extending the clinical ethics support that that CBC provides to all staff across the hospital as they work together in multi-disciplinary teams to provide health care for children and their families.

Nursing support and education

Ethics courses for nurses

In 2023 we continued to run our Ethics in Clinical Practice. This is an intensive in-person course over three full days. It aims to increase nurses' engagement, skills and confidence in clinical ethics discussions and decision making. The course covers key ethics topics relevant to nursing practice, including:

- ethical principles and frameworks
- asking ethical questions
- moral distress and regret
- deciding with children (including child's voice and truth-telling to children)
- ethical role of parents in decision making for their children

The course emphasises practical applications and skills, making extensive use of clinical scenarios. Two major simulations are run: a Clinical Ethics Response Group meeting, and a Communicating Ethical Concerns, which involves a professional actor and is supported by the RCH simulation team.

Comments from the course evaluation included:

Thank you so much! Feeling very inspired and ignited a passion I have even more appreciation for and eagerness to apply in my practice to support my patients and department.

Thank you for the breadth of knowledge Jenny, Lynn, Georgina, Sharon and John. The course was enriching and very valuable in learning more about clinical ethics from a patient perspective and from a staff perspective

LOVED it. Was so amazing and interesting. I would urge anyone to attend. The interaction and discussion was very engaging.

Ward support sessions

Jenny led regular ward support sessions (total of 22 in 2023) for nurses across six wards. This included continuing sessions for Sugarglider (post-PICU step-down ward), Cockatoo (neurology and neurodevelopment) and Butterfly (NICU) wards, and commencement of these sessions in Wallaby (home based care), Wombat (acute care) and Rosella (PICU). The sessions serve a number of purposes: ethics education, ethics support for cases on the

ward and ethics debrief. The sessions are developing the clinical ethics capacity of the nursing staff and familiarity with the CBC service. They also play a very important role in proactively addressing moral uncertainty, conflict and distress amongst nursing staff. In Rosella ward, Jenny is jointly facilitating regular sessions in collaboration with the Rosella psychologist. This co-facilitation of ethics and mental health is a model used in the USA to support staff with moral distress and allows staff to benefit from the joint expertise.

Ethics leadership, professional development and research

Nursing ethics support team (NEST) continued to meet regularly in 2023 under Jenny's leadership. The aim of this group is to up-skill and support bedside nurses as ethics champions on the wards. Its members are graduates of the Ethics in Clinical Practice Program.

Nursing members of the Clinical Ethics Response Group

The Clinical Ethics Response Group is a key part of the Clinical Ethics Service provided by the CBC. Members of the Clinical Ethics Response Group meet with referring clinicians to provide ethics case consultation for the most complex and challenging cases. Having a strong nursing input into these discussions is vital. In 2023 we identified that the nursing CERG membership could benefit from renewal, as numbers had dropped due to natural attrition. We put out a call for expressions of interest and were thrilled to be overwhelmed with applications, many from nurses who had completed the ECP course. We congratulate and welcome the following new nursing CERG members, five of whom are ECP graduates:

- Ms Rachel Tolan - Mental Health Senior Psychiatric Nurse
- Ms Ingrid Schulz - Palliative Care Clinical Nurse Consultant
- Mr Adam Rozsa - Neurology Clinical Nurse Consultant Stroke
- Ms Allison Ellis - Koala Ward Clinical Nurse Co-ordinator
- Ms Laura Tivendale - Sugarglider Nurse Coordinator
- Ms Jess Rowe - PICU/PIPER Clinical Nurse Specialist/Retrieval Nurse
- Ms Aaliya Fanham - PICU Registered Nurse

Nursing Members of the Clinical Ethics Committee

The Clinical Ethics Committee is an RCH committee which provides arms-length oversight and a community perspective on the work of the Clinical Ethics Committee. Community members and RCH clinical staff make up the membership of the Clinical Ethics Committee. Involvement of nurses attuned to the ethical aspects of clinical care is vital for the work of this committee. The three nursing members of this committee (two of whom have completed the ECP course) are:

- *Ms Helen Jowett (Nursing - Trauma Services, RCH)*
- *Ms Kathe Holmes (Nursing - Gastroenterology and Clinical Nutrition, RCH)*
- *Ms Catherine Wood (Nursing - Complex Care, RCH)*

Procedural Holding Symposium

Holding or restraining children for procedures is an ethically sensitive aspect of nursing practice. Jenny O'Neill initiated and organised this full-day symposium as a collaboration between Nursing Research and the Children's Bioethics centre, to promote reflection, sharing of experiences, and discussion of ethical best practice. The Symposium was held on Wednesday 29th November 2023 in the Ella Latham Theatre at RCH. Overall, there were 380 registrations for this day from across all states of Australia and New Zealand from a variety of backgrounds.

Dr Jenny O'Neill opens the Symposium



There was an exciting program of 12 oral presentations and 3 panel session with a mixture of research, case studies and reflections. Of the 15 presentations, 5 were from Melbourne Children Campus nurses with two prize winners – Dr Naomi Brockenshire and Ms Jaclyn Dorland, among them.

On the day following the symposium, a Research Collaboration workshop was held to identify ways to continue work on this ethically important issue.

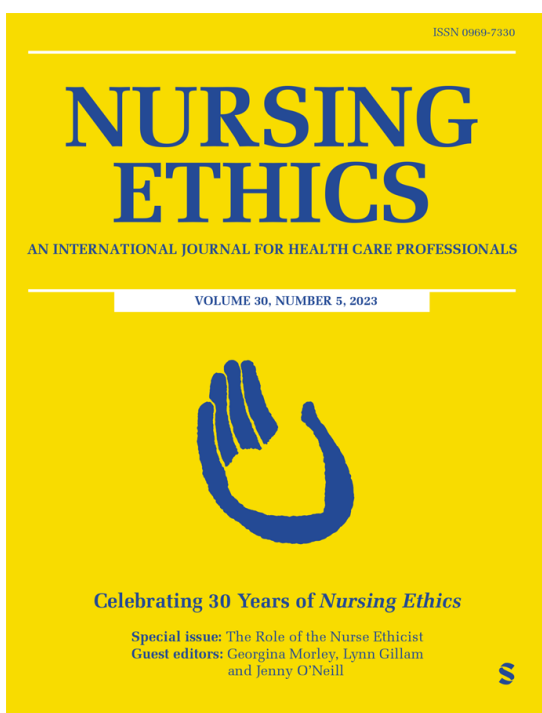
Jaclyn Dorland and Naomi Brockenshire receive their awards

Victorian Nurses and Midwives Trust Major Grant

Following on from the Procedural Holding Research Collaboration workshop, and in collaboration with the Department of Nursing Research, the CBC submitted a proposal for the Victorian Nurses and Midwives Trust Major Grant to explore best practice in the use of restraint to feed young people with Anorexia Nervosa admitted in an acute paediatric ward. We were thrilled to be the successful recipients. The project, titled *Guidelines for the use of Restraint in young people with Anorexia through Collaborative Engagement (grace)*, will commence in 2024, led by Jenny O’Neill.

Special issue of the international journal *Nursing Ethics*

Jenny O’Neill and Lynn Gillam, along with Georgina Morley (Nurse Ethicist at Cleveland Clinic Ohio) co-edited a special issue of the international journal *Nursing Ethics* on “The role of the Nurse Ethicist”, which was published September 2023. (The extract below from the editorial explains how this special issue had its origins in a Roundtable organised by Jenny O’Neill in 2021).



EDITORIAL

Georgina Morley, Lynn Gillam, Jenny O’Neill

In November 2021, while the pandemic still featured large across the globe, the Children’s Bioethics Centre at The Royal Children’s Hospital (RCH) in Melbourne, Australia circumnavigated logistical difficulties with international networking to host a two-hour “Nursing Ethics Virtual Roundtable.” This meeting was part of a project to explore ways of increasing engagement of nurses at RCH in clinical ethics discussions. The roundtable participants were the Australian paediatric bioethics team and ten invited nurses working in clinical ethics or what we assumed to be clinical ‘Nurse Ethicists’ from the USA. The primary aim of the roundtable was for the Australian service to learn from the US experience of supporting nurses in clinical ethics, given the value placed on nursing ethics in the American healthcare system is far in advance of Australia.

The roundtable explored a variety of topics beyond the engagement of nurses in clinical ethics, including governance and funding for ethics services, the misunderstandings of the role of an ethics consultation, and the nature of nursing moral distress. To the host team’s surprise, though, arguably the most robust discussion surrounded the label of “Nurse Ethicist.” There was a variety of opinions in the virtual room about the “pros” of using “Nurse Ethicist” as a title versus “cons” of such a label. This roundtable discussion has now led to this – a special issue on the role of the nurse ethicist.

11. Clinical Ethics Committee

The Clinical Ethics Committee (CEC) is an RCH committee which provides arms-length oversight and a community perspective on the work of the CEC. It is chaired by the Clinical Director of the CBC. The CEC meets quarterly to review a report of the clinical ethics referrals made in the preceding quarter, discuss de-identified versions of one or two key cases, and provides comments and insights about the processes and outcomes of these case consultations.

Community members

- Dr Heidi Nicholl
- Mr Chris Laird
- Ms Deborah Lawson
- Ms Sonya Rand
- Ms Sue Selwyn
- Hon Joseph Kay
- Ms Talya Masel

Youth member

- Mr Oli Pizzey-Stratford

RCH clinical staff members

- Dr Trisha Prentice (Consultant, NICU)
- Ms Robyn Clark (Social Work)
- Ms Dani Gold (Social Work – Family Violence)
- Ms Rebecca Peters (Nursing - Transition Support Service)
- Mr Paul Hammat (Spiritual Care)
- Ms Helen Little (Spiritual Care)
- Ms Helen Jowett (Nursing - Trauma Services, RCH)
- Ms Kathe Holmes (Nursing - Gastroenterology and Clinical Nutrition, RCH)
- Ms Catherine Wood (Nursing - Complex Care, RCH)

12. Reflections from CBC Visitors and Scholars



Mark Oliver

*Paediatric Gastroenterologist
Cystic Fibrosis (CF) and Pancreas Lead
Royal Children's Hospital*

Mark spent his sabbatical (August, 2023- January, 2024) incorporating time at the Clinical Bioethics Centre at the Royal Children's Hospital and the Uehiro Centre for Practical Ethics in Oxford. In addition to this he has supplemented his education in this field by enrolling and completing in part his Graduate Certificate in Bioethics at Monash University. This combination of experience has allowed him to clarify thoughts around clinical ethics in general but, also specifically the ethics of multiple organ transplant in people with CF, an area of great interest to him. He has, with considerable input from Lynn Gillam and John Massie and in collaboration with others in the field written a short opinion piece for publication which addresses the challenges faced by transplant teams in such situations.

Mark found his interactions with the entire group most edifying, and has gained insight into clinical ethics which he hopes to build on in the future.



Meaghan Storey

*Dual PhD Candidate, University of Manchester and University of Melbourne
August 2023-ongoing*

I have had the pleasure of spending the last 5 months interning with the Children's Bioethics Centre (CBC) at the Royal Children's Hospital. As a Cookson Scholars PhD candidate, I am fortunate to be supervised by Professor Lynn Gillam at the University of Melbourne. Lynn and the rest of the CBC team foster an incredibly welcoming and collaborative environment. The team invites visiting interns to critically engage with the clinical cases, work through the ethical challenges, and share their input in discussion. This collaborative environment has been invaluable to my current academic training and challenged my thinking as an aspiring ethicist. Interning alongside my PhD program has highlighted the nuance and complexity of clinical casework, which in turn has encouraged me to carefully consider the clinical implications and potential policy recommendations from my research. My time with the CBC has also solidified my career goals to work as a clinical ethicist following the completion of my PhD qualification.

The CBC does incredible work every day and it has been fantastic to be a small part of that team.



Erin Georgiou

Senior Occupational Therapist, The Royal Children's Hospital
Intern with the Children's Bioethics Centre
October 2023 – February 2022

I have been working as an OT at RCH since 2019. During this time, I have worked within many deeply challenging cases in my clinical role with the Complex Care team, which is where my initial interest in the field of Bioethics began. Having now moved through a range of clinical roles, I continue to carry bioethics with me. John Massie says, "once your eyes are opened, you see ethical situations everywhere!", and at RCH we find them around every corner.

I was extremely fortunate to be able to complete an internship with the CBC team as one of the final components of my Master of Bioethics through Monash Uni. While my studies so far (despite being challenging) have taught me a lot about frameworks for ethical analysis and problem solving, this internship allowed me to have a 'seat at the table' and see behind closed doors of the clinical ethics machine at RCH. I have a strong interest in the integration of bioethics conversations in routine allied health care and the immense value of inclusion of skilled allied health clinicians in ethically challenging discussions on patient care at RCH. Engagement with this internship at a local level has enhanced my theoretical study and grounding in clinical ethics. I've enjoyed my time with the ethics team so much so that it is in fact hard to let go. I look forward to continuing my involvement through the CERG, my final Masters project, and flying the clinical ethics flag in allied health (and beyond).



Tessa Holzman

Intern with the Children's Bioethics Centre 2023
PhD Candidate, Monash Bioethics Centre
May 2021-present

My six-month internship with the Children's Bioethics Centre is not the first time I've spent a stretch of time on a clinical ethics team, but in some ways, it felt like the first time because there's no place like it. Lynn Gillam and the rest of the team have been so welcoming, thoughtful, and encouraging that I never felt like 'just an intern', I always just felt like part of the team. The way they approach every case is thorough, empathetic, and rigorous. In situations where there can be so many clashing voices, the team is able to keep in mind the key questions and reduce the surrounding noise, without ever making anyone feel like they are not being heard. In addition to clinical ethics services, their education events are always accessible, non-judgmental, and extremely useful for practicing healthcare providers. As a PhD student in bioethics, I always leave these sessions having learned something I hadn't considered before, and something I can take with me in my research. More generally, I've learned so much about the many factors that go into what good care looks like, and how essential clinical ethics centres are to the smooth functioning of healthcare environments. In short, the CBC team has felt like a little home away from my research for the past six months, and I'm very sad to be leaving.

13. Academic Publications - CBC staff and students 2023

Barben, J., & **Massie, J.** (2023). Newborn screening for CF - The good, the bad and the ugly. *Journal of cystic fibrosis : official journal of the European Cystic Fibrosis Society*, 22(1), 5–6. <https://doi.org/10.1016/j.jcf.2023.01.011>

Barnard, E., **Gillam, L.**, Grover, S., & Guillemin, M. (2023). Understanding adolescent girls' and young women's health-seeking for female genital cosmetic surgery: How can clinicians help their patients? *Journal of Paediatrics and Child Health*, 59(1), 95-99.

Bart, A., **Hall, G. A.**, & **Gillam, L.** (2023). Gillick competence: an inadequate guide to the ethics of involving adolescents in decision-making. *Journal of Medical Ethics*.

El Ali, M., Licqurish, S., **O'Neill, J.**, & **Gillam, L.** (2023). Truth-telling to the seriously ill child—Nurses' experiences, attitudes, and beliefs. *Nursing Ethics*, 09697330231215952.

Feldman, S. L., & Johnston, C. (2023). Legal liability of clinical ethics services in Australia: "Should I be more worried than I am?" *JOURNAL OF LAW AND MEDICINE*, 30(2), 345–357.

Hall G. A. (2023). Reconceiving Reproduction: Removing "Rearing" From the Definition-and What This Means for ART. *Journal of bioethical inquiry*, 21(1), 117–129. <https://doi.org/10.1007/s11673-023-10281-4>

Jeffreys, J., Rahman, M., Vears, D., & **Massie, J.** (2023). Going home: Clinician perspectives on decision-making in paediatric home mechanical ventilation. *Journal of paediatrics and child health*, 59(3), 499–504. <https://doi.org/10.1111/jpc.16333>

Lynch, F., **Gillam, L.**, & Vears, D. F. (2023). Alleviating the confusion around content analysis: A comment in response to Wainstein, Elliott & Austin 2023. *Journal of Genetic Counseling*.

Marks, I. R., **O'Neill, J.**, **Gillam, L.**, & McCarthy, M. C. (2023). Ethical challenges faced by healthcare workers in pediatric oncology care during the COVID-19 pandemic in Australia. *Pediatric Blood & Cancer*, 70(2), e30114.

Massie J. (2023). Jumping in puddles and other goods of childhood. *Archives of disease in childhood*, 108(9), 689–690. <https://doi.org/10.1136/archdischild-2022-324314>

Massie J. (2023). Overcoming the burden of cystic fibrosis. *The Medical journal of Australia*, 218(3), 118–119. <https://doi.org/10.5694/mja2.51837>

McCallum, Z., **Delany, C.**, & **Gillam, L.** (2023). Crossing the line? Ethics of parenteral nutrition in paediatric neurodisability complicated by intestinal failure. *Archives of Disease in Childhood*, 108(1), 11-14.

McDougall, R., Warton, C., Chew, C., **Delany, C.**, Ko, D., & **Massie, J.** (2023). Visitor restrictions in hospitals during infectious disease outbreaks: An ethical approach to policy development and requests for exemptions. *Bioethics*, 37(7), 715–724.

<https://doi.org/10.1111/bioe.13188>

Mercurio, M. R., & **Gillam, L.** (2023). Ethics at the End of Life in the Newborn Intensive Care Unit: Conversations and Decisions. In *Seminars in Fetal and Neonatal Medicine* p. 101438

Schulz, I., **O'Neill, J.**, Gillam, P., & **Gillam, L.** (2023). The scope of ethical dilemmas in paediatric nursing: a survey of nurses from a tertiary paediatric centre in Australia. *Nursing Ethics*, 09697330231153916.

Spriggs, M. (2023). Children and bioethics: clarifying consent and assent in medical and research settings. *British Medical Bulletin*, Idac038.

Vemuri, S., Heywood, M., **O'Neill, J.**, Hynson, J., Williams, K., & **Gillam, L.** (2023). Qualitative study of paediatric advance care planning through simulation: how we did it and the lessons learned. *International Journal of Qualitative Methods*, 22, 16094069231193262.

Vemuri, S., Hynson, J., Williams, K., & **Gillam, L.** (2023). Navigating two 'truths': a qualitative study of physician-led end-of-life decision-making for children with life-limiting conditions. *Archives of Disease in Childhood*.

Vemuri, S., Hynson, J., Williams, K., **O'Neill, J.**, & **Gillam, L.** (2023). Shepherding parents to prepare for end-of-life decision-making: a critical phenomenological study of the communication approach of paediatricians caring for children with life-limiting conditions in Australia. *BMJ open*, 13(12), e075740.

Vemuri, S., **O'Neill, J.**, Hynson, J., Williams, K., & **Gillam, L.** (2023). Is Simulation as an Investigative Method as Good as Reality?. *International Journal of Qualitative Methods*, 22, 16094069231207770.

Vemuri, S., **O'Neill, J.**, Hynson, J., & **Gillam, L.** (2023). Informing simulation design: a qualitative phenomenological study of the experiences of bereaved parents and actors. *Simulation in Healthcare*, 18(2), 75-81.

14. Acknowledgement of our supporters

We would like to express our gratitude to all those who support the work of the Children's Bioethics Centre.

The Royal Children's Hospital Foundation through the Betty Cosgrove Endowment

Betty Cosgrove passed away in 2016 and left her estate to The Royal Children's Hospital Foundation. The RCH Foundation gave careful thought to how her generosity could have an enduring legacy on the lives of all our patients and bequeathed the estate to fund the RCH Children's Bioethics Centre. Betty Cosgrove was described by friends and family to be a strong, fiercely independent woman who cared deeply about family. Betty's generous gift has helped strengthen advocacy for the children, family and staff of the RCH.



Friends of the CBC Auxiliaries (FoCBC)

Mr Robbie Friedman, President

Mr Ric Comber, Treasurer

The Friends of the CBC Auxiliary has had another positive year in 2023, with growth in membership, funds continuing to grow, and an increasing range of fun and engaging activities. This has helped the CBC to continue to increase its activities, coverage and Bioethics services throughout the RCH and beyond.

In the past year, we have been able to support the CBC with \$58,000 for a CBC Ethics Education Officer, \$4,800 on new episodes of the 'Essential Ethics' podcast, and \$1,200 on e-learning modules. We also support the CBC's annual conference, in particular hosting the CBC hypothetical on the evening of the first day of conference. The moderators, Prof Lynn Gillam and Prof John Massie, invite attendees to participate in the difficult considerations, discussions, and decisions that may be faced by patients, families, medical and allied health teams, amongst others, during critical moments.

Our Friends of the CBC increased in number by approximately 40 to 301 in total. Two highlights on the Friends of the CBC calendar in 2023 Charity Golf Day and the inaugural Sailing Day. The Golf Day in May attracted many players and raised approximately \$23,000. Our sincere thanks to Officers at the Albert Park Golf Course, Mr Sam Adams and Ms Lisa Wen, our Sponsors, a special thanks to the generosity of the Beck Property Group, and lastly but very importantly the players. We look forward to the upcoming Golf Day on Tue, October 2nd, 2024!

2023 saw a new event added to our annual calendar: the Inaugural Charity Sailing Day. Supporters had the opportunity to participate in a grand yachting regatta on Port Phillip Bay in December, racing on yachts with experienced crews from the Sandringham Yacht club, including a yacht or two that just a few weeks later competed in the Sydney-Hobart Race! A wonderful day of sailing, followed by drinks and canapes overlooking the bay, the day raised approximately \$20,000 for the Children's Bioethics Centre. We look forward to the 2024 Sailing Day on Friday, 29th November.

My thanks to our incredible Team, Ric Comber, Renate Wolf, Masoomah Wake, and David Kolieb, as well as Barry Novy AO and Dr Hugo Gold, and of course the CBC Clinical team, Professor Lynn Gillam and Professor John Massie and the CBC staff. My thanks and appreciation also to Lucia Di Maio at the RCH Foundation for her excellent support.

Mr Robbie Friedman, President

The Humanity Foundation



The Humanity Foundation
generously supports the
National Paediatric Bioethics
Conference.