

EPIC Newsletter

August 2025



EPIC Moments You'll Want to Know About

UPCOMING EVENTS

Welcome to the first edition of the National Health and Medical Research Council (NHMRC) Centre of Research Excellence (CRE) newsletter. This will be your go-to space for Extremely Preterm Infant (EPIC) news, inspiration and opportunities to connect with our team.

We will share updates, highlight the incredible people and partnerships driving EPIC progress, and introduce the new teams of our CRE, including Knowledge Translation (KT) and Education Committees (EDU) along with updates from our Lived Experience Network (LEN) supporting the EPIC community.

EPIC builds upon the strong foundation established by the Newborn Medicine CRE, with renewed emphasis on knowledge translation, education and elevating lived experience voices and engagement.

The EPIC team would like to extend our heartfelt thanks to all our investigators, lived experience members, researchers, clinicians and all our partners for their hard work across clinical trials, past and present CREs and current research. We are committed to turning research into real-world care accessible and actionable for families, health professionals and service providers.

The first edition celebrates a major milestone in our mission to tackle the biggest challenges for our tiniest babies: the NHMRC approval of national guidelines for growth, health and development follow up in children born very preterm.

This is the result of 18 months of dedicated work led by the CRE in Newborn Medicine, aiming to improve post-discharge care for over 3,000 very preterm babies born annually in Australia.

Congratulations to Professor Jeanie Cheong, collaborators, experts, families and health professionals. Their collective effort has produced an outstanding evidence-based framework to support equitable health and developmental follow-up for children born very preterm, is now beginning its implementation across Australia. You can read more in the June 14th [edition of AusDoc](#) or [navigate here to access the guidelines](#) directly.

A key step towards ensuring consistent, high-quality care beyond the hospital – an area where families have told us is often overlooked.

We aim to keep improving and listening to generate relevant, impactful, sustainable care practises which hope to empower clinician's, support families and inform health systems.

We hope you enjoy our first edition. Welcome to the EPIC family!

Megan Morales
EPIC Project Coordinator

Save the date

EPIC Investigators Meeting for EPIC -
For all CI, AI & EPIC Collaborators (9am-12pm Virtual)
- OCTOBER 15, 2025

Cool Topics in Neonatology 2025
(Melbourne)
- NOVEMBER 27-29, 2025

Research Connections
(Melbourne)
- NOVEMBER 29, 2025
9-12:30pm,
Ella Latham Auditorium, RCH

EPIC Investigators Meeting
(All CI, AI & EPIC Collaborators- Face - Face, Melbourne)
- NOVEMBER 2026*
More information coming

Knowledge Translation at EPIC: Turning Research into Impact

Kate Claydon-Platt & Evi Muggli,
EPIC Knowledge Translation Leads

The work of the Knowledge Translation (KT) team ensures that research leads to real improvements in the care of babies born extremely preterm. Our mission is to translate high-quality evidence into practical tools, policies, and models of care that support clinicians, families, and health systems. We are now focused on implementing the Australian Developmental Follow-up Guideline for Children Born Very Preterm in clinical and service settings. Our initial work is centred on embedding the guideline into routine care by understanding local contexts and supporting its adoption by health professionals and service providers.

We are leading two new national guideline initiatives: the Australian Living Guidelines for the Management of Respiratory Distress Syndrome (RDS) in Newborns and a new guideline focused on the health and developmental needs of people born extremely preterm as they move through adolescence and into adulthood. These new initiatives will help reduce variability in care, promote best practice, and support better outcomes across the life course. Keep an eye out for future KT updates as we share new resources, implementation tools, and opportunities to get involved.

Education at EPIC: From Incubator to Impact

Ju-Lee Oei, Shiraz Badurdeen & Tugba Alarcon-Martinez,
EPIC Education Leads

The EPIC Education Sub-Committee is working to complement and enhance preterm health education across Australia by identifying gaps and creating innovative approaches to reach broader audiences. Rather than duplicating existing resources, our focus will be two-fold. First, to develop multimedia educational content that serves three key groups: healthcare professionals, families with lived experience, and neonatal researchers. Second, to develop outreach initiatives for multicultural access to preterm community beyond Australia.

As we prepare for our upcoming strategy workshop in August, we're conducting assessments across our target audiences to ensure our educational priorities align with real-world gaps in preterm health knowledge and access.

Look out for our upcoming education needs survey.



EVENT HIGHLIGHT

Showcasing “Cool Topics in Neonatology” -November 27-29, 2025

Interview with Rachel Brooks (Cool Topics organising team & Neonatal Research Nurse, Clinical Nurse Specialist, The Royal Women's Hospital)

As we look ahead to the 2025 *Cool Topics in Neonatology* -Australia's largest gathering of neonatal professionals—we spoke with the organisers to get a behind-the-scenes look at what attendees can expect this November.

What excites you most about this year's Cool Topics program? This year's program is exceptionally rich, featuring world-renowned international speakers and a broad spectrum of topics—from birth through to long-term follow-up. What excites me is the growing presence of lived experience in neonatal research. Cool Topics doesn't just spotlight these voices—it empowers them to actively shape the conversation.

Are there any new or emerging topics being covered this year? Yes, and they're incredibly promising. We'll be showcasing several major trial results, including:

- COSI-2 Trial: Investigating coconut oil's potential in preventing neonatal sepsis
- AIROPLANE Trial: Exploring respiratory support strategies
- TORPIDO 30/60 Randomised control trial comparing outcomes for infants with two initial oxygen concentrations to support preterm babies.

Which keynote speakers or sessions are you most looking forward to? I'm excited to hear from Professor Neena Modi, whose work in neonatal policy and advocacy is globally recognised. Professor Anup Katheria—renowned for his pioneering research in neonatal resuscitation—will lead a hands-on workshop on Saturday, offering attendees a rare chance to learn directly from a global leader.

How does Cool Topics foster collaboration across sectors? The conference is designed to be inclusive and multidisciplinary, welcoming clinicians, researchers, allied health professionals, families, and those with lived experience. We're proud to explore not only clinical research, but broader themes such as maternal health and national preterm birth prevention strategies. It's a space for diverse voices and meaningful collaboration.

Any advice for first-time attendees? Arrive with an open mind. The atmosphere is warm and welcoming, and we encourage everyone to connect, share, and learn. Whether you're a seasoned professional or new to neonatology, there's a place for you here. (*Program & registration on the Royal Women's Hospital website*)

Introducing Loni Binstock

Researcher, EPIC Executive Committee Member, Lived Experience Network Co-Facilitator & Mum of preterm twin boys.

I'm a mum of four, including twin boys who were born extremely preterm at 25 weeks and are now 9 years old. That experience brought me into the world of research and to EPIC. I'm passionate about improving outcomes for children born prematurely and giving back to the community that supported our family. At EPIC, I bring the lived experience perspective to the Executive team and help shape our research agenda through that lens. I also co-facilitate the Lived Experience Network with Abbey Eales, helping to nurture and amplify the voices of families like mine.



What's been the most rewarding part of being involved with the CRE?

Supporting preterm kids to thrive is deeply personal for me. It's incredibly rewarding to be part of research that is improving long-term outcomes and to work alongside people who genuinely care.

Looking back at your preterm experience, what's one piece of advice you wish you had?

We spent 5 months in NICU with the twins, who then came home on breathing support for another four months. And from there it has been an ongoing journey of many, many medical and health appointments. While we were in NICU, we had incredible support from health care professionals, social workers, Life's Little Treasures, family and friends. I wish I'd had the chance to speak with parents who'd been through it—people who could share their stories, show how their kids were doing, and help us feel less alone in the decision-making. For example, here's my 19-year-old son who was born preterm. He is doing really well today. Just finished school and loves playing tennis. To hear it hasn't necessarily been easy despite lots of medical interventions, he did go to school with his peers. Lived experience alongside medical advice would've made a huge difference to our confidence and wellbeing. It felt very isolating in moments when we received information and were faced with big decisions.

What's your vision for the future of lived experience in research?

I believe we can keep shifting the tide—where people with lived experience are meaningfully integrated into research. That means creating safe, inclusive spaces, ensuring they're part of investigator teams, and helping shape the research we do in EPIC. One key way to make that happen is by continuing to nurture and grow our Lived Experience Network. EPIC has laid a strong foundation, and with the right people in place, we have a real opportunity over the next five years to lead the way in true collaboration between researchers and those with lived experience.

Lived Experience Network

Abbey Eeles & Loni Binstock
Lived Experience Network Co-Facilitators

The Consumer Advisory Group has undergone an exciting transformation, voting to change their name to the Lived Experience Network (LEN). The LEN has been actively engaged in several important initiatives over the past few months. A key focus has been revising the "Working Together Agreement" and developing a comprehensive LEN policy to guide operations and ensure that LEN voices are effectively integrated into EPIC's research activities. Additionally, the LEN has played a pivotal role in planning for the annual Research Connection Conference, selecting the theme "The Right Intervention at the Right Time." [Register via Cool Topics eventbrite to secure your free tickets.](#)

To help introduce the LEN members to the wider research community, short bios will be featured on the new EPIC website, providing insights into their diverse backgrounds and experiences.

LEN Co-facilitator Dr. Abbey Eeles also represented the LEN's perspectives at the roundtable discussion on the NHMRC draft statement on consumer and community involvement in health and medical research.

Notably, the LEN is currently developing a research protocol and survey questions for the international study "Voices of the NICU Generation: Adults' Priorities for Newborn Research." This ground-breaking study aims to understand the research priorities of adults who were born prematurely, ensuring that their unique perspectives shape the direction of future newborn research. The LEN's contributions are invaluable in ensuring that EPIC's research agenda and activities are informed by lived experiences of those directly impacted by preterm birth, ultimately leading to research that is relevant, meaningful, and aligned with the needs of the community.

The Research Connection

Embedding Lived Experience in Research

Saturday, November 29
9:30AM - 1:00PM

Hosted by the Extremely Preterm Infant Centre of Research Excellence (EPIC), in collaboration with Cool Topics

The Right Intervention at the Right Time

Join us for a transformative half-day conference bringing together researchers and families navigating their own preterm journeys. Explore innovative, evidence-based interventions that improve outcomes for children born preterm and their families. Together, we'll examine proven approaches and emerging strategies that make a real difference throughout the premature life journey.

Expert Panels

Dynamic discussions between families and researchers on cutting edge interventions and their real world impact

Community Connection

Network with families, researchers, and advocates passionate about improving outcomes for children born preterm

Research Insight Sprint

Experience a series of 7 minute rapid-fire research presentations where Researchers share their work in relatable, plain language! You'll be part of the action by helping to evaluate how clearly and effectively they communicate their findings, to find the people's choice. Whether you're a clinician, researcher, parent, or community member, your perspective matters!

Key Intervention Areas

- Neurodevelopmental outcomes
- Lung health & respiratory outcomes
- Medical interventions in the NICU
- Parent wellbeing support
- Preschool interventions
- Middle childhood (6-12 years)

REGISTER TODAY - LIMITED SPACES AVAILABLE - FREE EVENT



PhD Highlights



Dr Cassidy Du Berry

BSc(Hons), PGCert, CRFS, PhD

Hello! I'm Cassidy, an early career researcher and respiratory scientist. I'm originally from County Wicklow (also known as the 'Garden of Ireland') but have called Melbourne my home for the last six years. Currently, I work as a Research Fellow at Monash University and as Deputy Head Scientist of Lung Function Services at The Royal Children's Hospital. I was awarded my PhD in February of this year, where I examined the lung function and physical activity levels of school-aged children born moderate to late preterm (32 to 36 weeks' gestation). I fell into preterm research through my clinical work, where I'd encounter patients born preterm presenting for lung function assessment. I found these children and their families to be awash with kindness, enthusiasm and curiosity, and I wanted to do more to help them.

While much of my work to date has focused on more 'gestationally mature' preterm infants, I've been increasingly involved in research concerning the effects of extremely and very preterm birth on lifelong lung health. Currently, I'm working on a viewpoint for a prominent medical journal in my field, aimed at characterising life-course lung function trajectories of individuals born preterm. I'm also involved in some exciting and emerging clinical trials, focused on reducing lower respiratory tract infections and identifying the different clinical phenotypes (traits and features) of infants born preterm.

When you're so far from family (17,000 odd kilometres!), establishing yourself as an early-career researcher can certainly have its ups, downs, and challenges. However, since first starting this journey in 2021, I've been completely blown away by the support I've received from all the fantastic individuals who make up EPIC. Looking ahead, I hope my work can help identify babies born too soon who are at greatest risk of lung problems later in life—and, importantly, guide early-life interventions designed to improve lifelong lung health.



Dr Lauren Rossetti

BPsych (Hons), PhD (Clinical Neuropsychology), Psychologist (Clinical Neuropsychology Registrar)

I'm Lauren, a post-doctoral researcher with the Victorian Infant Brain Studies (VIBeS) group at MCRI and a clinical neuropsychology registrar at the Child and Adolescent Neuropsychology Group. My days are spent juggling research and working clinically as a psychologist, as well as co-hosting a psychology podcast, called *This Might Help*. My journey into preterm research began with the question: how can I best support children who have had a challenging start to life? Through both my research and clinical work, I've witnessed firsthand how preterm birth impacts not just the child, but the entire family unit, and one of my favourite parts of my work is getting to know and support both caregivers and their children.

I recently completed my PhD, which explored executive function (those problem-solving, planning, and complex attention skills) at school age, in children born moderate-to-late preterm. I've enjoyed expanding my work this year and exploring academic outcomes in preterm children, as well as looking at school-age outcomes across the entire gestational spectrum, from very preterm to late preterm birth. One of the greatest benefits of being a clinician-researcher is seeing how my clinical and research work overlap and inform each other. Clinically, I work with neurodiverse young people, and I hope to expand my research into exploring how we can best support neurodiverse children with a history of being born preterm or who experience other early life complications.

Looking ahead, I'm hopeful my research will help identifying which children are at greatest risk for thinking and learning challenges and then putting the right early interventions in place. My big goal is making sure these remarkable children have every opportunity to flourish and succeed at school, whatever form that success takes for each individual child.

JOIN OUR MAILING LIST
EPIC_CRE@MCRI.EDU.AU

EPIC CRE has a call out for funding opportunities for People and Project grants in preterm research (4th August until September 5th). Look out for our announcement or email EPIC_CRE@mcri.edu.au for more information.