ISSUE #2

EPIC Newsletter

December 2025

EPIC Moments You'll Want to Know About

The CRE has been buzzing with activity as we wrap up 2025 on a high note.

On the research front, our team has celebrated incredible success with grants and awards. Congratulations to our large multidisciplinary team for these outstanding accomplishments.

The CRE provided early career research project and PhD student funding support for 2026. The quality and depth of the proposals was outstanding, making the selection process incredibly challenging. Congratulations to all the recent awardees. We look forward to seeing the impact of your projects.

Beyond our internal walls we have been active with our external collaborators. We partnered with Life's Little Treasures Foundation, supported fundraising and awareness through the Mighty Trek Challenge throughout October and helped host a morning tea for Prematurity Day November 17th.

In partnership with Miracle Babies Foundation and The University of Melbourne, The Neonatal Critical Care Alliance was formed in August to champion Paid Parental Leave legislation in Australia. Learn more about the parliamentary working group and how you can get involved.

The Research Connection Conference, November 29th, led by the Lived Experience Network, showcased inspiring projects, panel discussions and up and coming research. Alicia Spittle's standout keynote on research literacy was fun and engaging, beautifully setting the tone for this year's theme, "The Right Intervention at the Right Time".

Lived experience is the foundation for building safe, inclusive systems. If we want meaningful lasting accountable change, those who have walked the hardest paths must be the ones shaping the map. Thank you to the EPIC community for its commitment to understanding and improving outcomes in babies born preterm.

Thank you to everyone who joined the Virtual Investigators Day Launch on October 15. EPIC teams came together to share introductions and updates across the CRE.

Highlights include:

- Insights from the Lived Experience Network
- Updates on the Knowledge Translation guideline activities
- Presentations from researchers Dr. Free Coulston (P-POD Evaluation Survey) and Dr. Cassidy Du Berry (Caregiver perspectives on home oxygen therapy in infants with BPD).

We'd love your feedback on Investigator's Day! Did we cover the right content? What would you like to hear more about? How can we improve? Your input is invaluable in helping us shape future events. All responses are anonymous, please share your thoughts in this 5 minute survey.

We hope this newsletter will inform and inspire you as we head into 2026.

Megan Morales
EPIC Project Coordinator

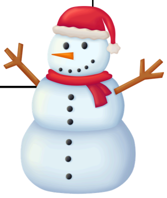
UPDATES & WELL WISHES

Centre of Research Excellence
Extremely Preterm Infant

Updated Logo for Community Use

We're excited to share that EPIC now has an updated logo designed for community use. If you'd like a copy or need guidance on how to use it, please reach out.

Its been a pleasure working with you all in 2025. Wishing you a safe, beautiful festive season and fantastic 2026.



Awareness and uptake of the 2024 Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm

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

We surveyed 48 Australian and New Zealand Neonatal Network (ANZNN) members; neonatologists, paediatricians, and physiotherapists to assess awareness and implementation of the NHMRC-endorsed 2024 Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm and help identify strategies to maximise uptake.

Nearly 70% (n=33) are aware of the guideline, while 46% (n=22) were already applying its recommendations. Suggested strategies to support implementation included quick reference guides, promotional materials, electronic medical record alerts, education sessions and case studies.

Guideline awareness is encouraging. Drawing on successful past implementations, respondents recommended robust communication, broad promotion, and adequate funding to drive uptake and service-level changes. Combined with ongoing education, practical resources, and system-level support, these strategies will enable health professionals to deliver best-practice care for very preterm children and their families. The Guideline is available on the Extremely Preterm Infant CRE website.

Current work includes developing two new NHMRC-endorsed guidelines for acute NICU care (respiratory distress syndrome) and for extended follow-up through to adulthood. Work is also underway to assist implementation of the existing developmental follow-up guideline.

PLATFORM HIGHLIGHT

raisingchildren.net.au
the australian parenting website

Celebrating Raising Children Network: 20 Years of trusted Parenting Support

A conversation with Edwina Buckle, Strategic Partnerships & Impact at Raising Children's Network (RCN).

Next year marks a remarkable milestone for the Raising Children Network (RCN) celebrating 20 years of empowering Australian families with trusted, evidence-based parenting support. Founded in 2006 through a collaboration between the Murdoch Children's Research Institute, Parenting Research Centre and Smart Population Foundation, with funding from the Australian government, RCN has grown into Australia's leading digital parenting platform. In 2024, RCN website resources were viewed over 35.7 million times, the Raising Healthy Minds app was downloaded by over 40,000 families, and over 1000+ pieces of content are licenced through strategic partnerships with the jurisdictions, research institutions and UNICEF. This growth reflects RCN's enduring commitment to relevant, accessible, inclusive, research-backed resources which are easy to digest which support families at every stage.

How has the digital parenting landscape changed since the platform launched?
RCN has evolved from a static platform focused on children aged 0–5 into a dynamic, multi-channel resource spanning pregnancy through to 18 years, with dedicated content on Autism, ADHD and Disability. Initially, the approach was simple: build a website and parents would come. Today, we meet parents in the digital and community spaces they already inhabit and add value to those everyday experiences. This includes partnering with the ABC to extend themes from the Maggie Dent hosted 'Role of a Lifetime' parenting show, achieving a 220% month-on-month increase in parents accessing RCN through ChatGPT, and showing up consistently across social media, LinkedIn, early educational platforms like Story Park, and trusted community channels such as playgroups and maternal and child health services.

How does RCN ensure its content resonates with its community?
RCN's collaborates with over 400 experts to develop scientifically validated content, translated into plain language for accessibility. Inclusivity is central, resources are culturally adapted, multilingual, and tailored for Aboriginal and Torres Strait Islander families, low-literacy users, people with disabilities, and diverse family structures. We co-create sensitive content with parents and carers, such as resources on birth trauma, ensuring lived experience is meaningfully reflected. Feedback is continuously gathered, helping shape content that resonates with real-life needs. A dedicated suite of resources supports families navigating preterm birth and NICU journeys, developed with expert input from EPIC CRE's Dr. Louise Owen.

As RCN marks 20 years, what's next?
RCN's future is about deepening its reach and reimagining how families connect with trusted information. Parents want support that's immediate, practical, and part of everyday life. We're shifting towards video-led formats that bring evidence-based advice to life through relatable stories, while exploring AI to personalise content and enhance accessibility. Beyond digital, we're meeting parents in the spaces they already inhabit, online platforms, community services and everyday settings. Our ambition remains clear: to ensure every Australian parent and carer has access to trusted, evidence-based child health and development information.

Celebrating our Lived Experience Network

A year of Partnership and Growth

Abbey Eeles & Loni Binstock
Lived Experience Network Co-Facilitators

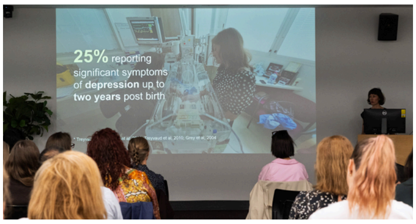
This year has been transformative for EPIC's Lived Experience Network (LEN). In mid-2024, we held a pivotal strategy workshop facilitated by Ken Knight, Head of Research Impact & Consumer Involvement at Murdoch Children's Research Institute. This session demonstrated our commitment to meaningful partnership and extending ourselves further along the [International Association of Public Participation (IAP2) spectrum.]() Together, we explored the LEN's vision within EPIC, identified needs for active participation, and collaboratively revised the EPIC mission statement to ensure it truly reflects the values and goals of both researchers and people with lived experience.

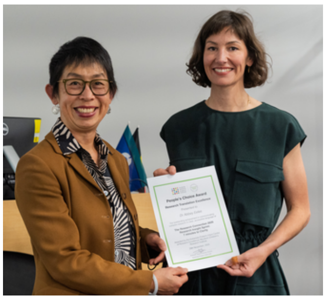
The fruits of this partnership were evident at our second annual Research Connection Conference on November 29th—an event born from the vision and dedication of LEN members. This year's theme, "The Right Intervention at the Right Time," brought together our community to explore evidence-based interventions. Professor Alicia Spittle's keynote equipped attendees with practical skills to evaluate interventions, while our Research Insight Sprint showcased six studies spanning parent mental health, attachment, physical activity, and respiratory care.

Dr Abbey Eeles received the People's Choice Award for her compelling presentation on mindful self-compassion for NICU parents, exemplifying research that truly bridges science and lived experience.

Feedback from the conference has been positive and we look forward to hosting it again in 2026, further enriching the connections between Lived Experience and the world of research.

LEN Members present at the 2025 Research Connection Conference



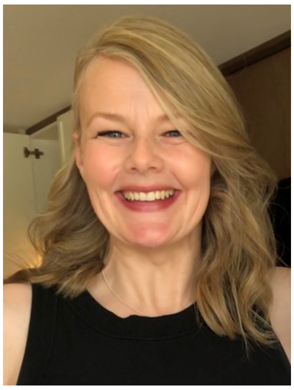


Prof. Jeanie Cheong & Dr. Abbey Eeles (People's Choice Award Winner 2025)

Thank you to Cassidy Du Berry for capturing photos of the event.

Introducing Jess Jackson

Child Mental Health Support worker, Lived Experience Network Member & Mum to a child born preterm.



I'm Jess, I'm the mum of a beautiful seven-year-old boy who was born preterm. He had complex medical needs which came with a lot of challenges. He is just so funny, kind, adventurous and brave. It's such a privilege to be his mum and see him make his way in the world. I joined in 2024 as a member of the Lived Experience Network (LEN) which marked my entry into lived experience work. My role follows my passion in Infant and Child Mental Health as a support worker for parents and families.

What's been the most rewarding part of being involved with the CRE?
Being a part of the LEN has filled me with so much purpose. I wasn't aware that this opportunity was out there until I met with Alicia Spittle and she invited me to join. There's been so much I've loved. Collaborating with families who've had similar journeys to me has been incredibly special and touched my heart. Meeting grown-up Premies has been so inspiring; they bring so much hope. Working alongside passionate researchers and clinicians has been brilliant, especially seeing it come together last year at our first Research Connection conference (which was bigger and better this year). Being a part of research projects like Active Prem was a great learning curve. It was my first, and the team was so supportive. I got to co-design the coach program and help with content, which was so much fun. Personally, seeing how karate helped my son socially, emotionally and physically made me even more motivated to help other families have similar experiences.

Looking back at your preterm experience, what's one piece of advice you wish you had?
We were wonderfully supported by NICU staff, but I wish we'd had more education and awareness about how the NICU experience might affect our child long-term, especially socially and emotionally. When my son started struggling with anxiety in kindergarten, we didn't immediately realise it could be linked to those early days. Back in 2018 when we were in hospital (for 102 days), we were often told "lucky he won't remember this!" I believe we can only benefit from more awareness of how the many stressors in NICU may impact a child's mental health as they grow. Let's empower families with the tools and guidance to help their babies heal sooner. Thankfully for our family, we found great mental health resources and got the support we needed. It also helped our son to join karate and get a puppy. Animals can be the best therapy and now they're best friends!

Celebrating World Prematurity Day 2025

Written by Maggie Llyod. Text and photos kindly added with permission.

A heartfelt thank you to the Royal Women's Hospital for welcoming us and allowing us to support the morning tea alongside Life's Little Treasures (Maggie Lloyd & Amy Baker) who did an exceptional job.

"World Prematurity Day (WPD) 2025 theme "Give preterm babies a strong start for a brighter future."

This message reminds us just how vital it is to support the health and wellbeing of preterm babies from the very beginning. Ensuring every baby has the best possible start in life is not only a moral responsibility – it's an investment in stronger, healthier, and more resilient communities around the world. This year's World Prematurity Day is particularly significant.

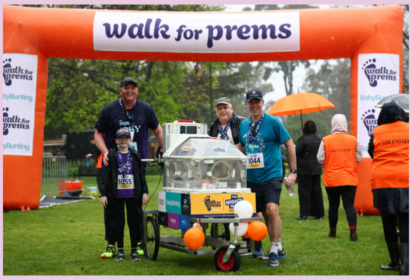
The World Health Assembly has officially added November 17 to the WHO global health calendar. This recognition marks a major milestone – one that urges governments across the world to prioritise preterm birth as a critical health issue. It strengthens our collective mission and reinforces the understanding that improving outcomes for babies born preterm is a global responsibility, one that requires collaboration, investment, and long-term commitment.

A special thanks to the incredible Neonatal teams for their continued dedication and compassionate care for our most vulnerable babies." - Maggie Llyod

EPIC Researchers & Life's Little Treasures Team

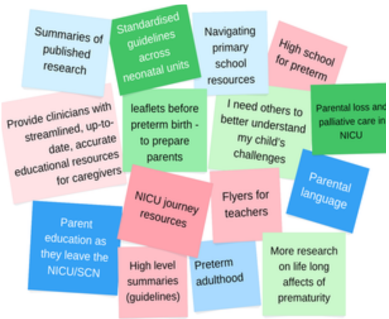
From left to right: Dr. Cassidy Du Berry, Dr. Abbey Eeles, Loni Binstock, Prof. Alicia Spittle, Prof. Jeanie Cheong & Maggie Lloyd (Life's Little Treasures)

To find out more about Life's Little Treasure's Foundation and the recent Melbourne Walk for Prems - The Mighty Trek Challenge where a number of EPIC members attended and participated (and got thoroughly soaked!).



Education: From Incubator to Impact

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



Thank you to everyone who responded to our recent community education survey. Your input (N=50) has been invaluable in helping us identify gaps in neonatal education, understand current resource use, and uncover challenges faced by those caring for extremely preterm infants.

The Education team has used the information to perform a gap analysis of existing resources across the CRE. We selected 5 education priorities and highlighted opportunities to address current gaps across the preterm health community.

Looking ahead to 2026, we would like to generate a podcast and video resources in collaboration with the Royal Children's Hospital Education Hub. We are keen to engage in thoughtful conversations with lived experience network members and leaders in research literacy and translation. We will explore the challenges and opportunities for effective engagement ideal for successful research translation. If you have specific skills, hidden creative talents and or language fluency that could support content generation we would love to hear from you!

Neonatal Critical Care Alliance

Advocating and raising awareness of the Paid Parental Leave (PPL) legislation in Australia - Dr. Abbey Eeles.

Building Momentum for Neonatal Families: The Critical Care Alliance and Extended Paid Parental Leave Campaign.
For four years now, The Extremely Preterm Infant Centre of Research Excellence (EPIC), together with The University of Melbourne, has championed a critical cause: ensuring families with babies in neonatal critical care receive the support they desperately need through extension of the Australian Government's Paid Parental Leave Act. Earlier this year, our advocacy work reached a pivotal moment with the establishment of the Neonatal Critical Care Alliance.

What is the Alliance?
The Alliance brings together six organisations—The University of Melbourne, Miracle Babies Foundation, Tresillian Family Care Centres, Birth Trauma Australia, HeartKids Limited, and Cerebral Palsy Alliance—united by a shared vision. Our collective aim is to expand support for vulnerable babies and families during neonatal critical care hospitalisation.

Approximately 15,000 Australian babies require hospitalisation for more than two weeks annually. Parents of these babies often exhaust their paid parental leave before bringing their babies home, forcing many to return to work prematurely. This separation during a critical developmental period increases risks of parental anxiety, depression, and compromised child development. We're calling for the Australian Paid Parental Leave Act to be amended, allowing primary carers one week of extra paid leave per week hospitalised (up to 14 weeks maximum), and secondary carers an additional two weeks. The estimated cost, $44 million represents less than 1% of the Government's 2026-2027 budget, with long-term benefits far exceeding costs.

Our November roundtable at Parliament House generated overwhelming support. An in-parliament working group has been established, including Dr Mike Freelander MP, Senator Anne Ruston, Senator David Pocock, Dr Monique Ryan MP, Senator Larissa Waters, and Zali Stegall MP.

Join Us—Make a Difference
Your lived experience in neonatal hospitalisation, work in healthcare, or simply believe in supporting vulnerable families, there are multiple ways to get involved. Your contribution through direct advocacy, sharing your story, or organisational endorsement strengthens our collective voice and brings us closer to meaningful policy change.

Families with lived experience: Contact your Federal MP: Find your MP by entering your postcode. Use our template letter to advocate for change, personalise it with your story. **Share your story**: Complete our support form to help us demonstrate the real impact on families. Your voice strengthens our message to government.
Health professionals: Your clinical expertise, professional perspective and patient insights are invaluable; healthcare professional form.

Organisations: Endorse the Critical Care Alliance and join our growing movement for change.
Support our message: Sign our digital petition to show your backing.
(First names removed; state and position shared publicly.)

Together, we're creating real change for Australia's most vulnerable babies and families.

Article and photo kindly added with permission from Dr. Abbey Eeles.
From left to right: Professor Alicia Spittle (Member of EPIC executive), Professor Jeanie Cheong (Director of EPIC), Dr Monique Ryan MP, Kylie Pussell (CEO, Miracle Babies Foundation), Dr Abbey Eeles (Lived Experience Network Co-Chair, EPIC)

Congratulation's to successful CRE scholarship awardees for 2025

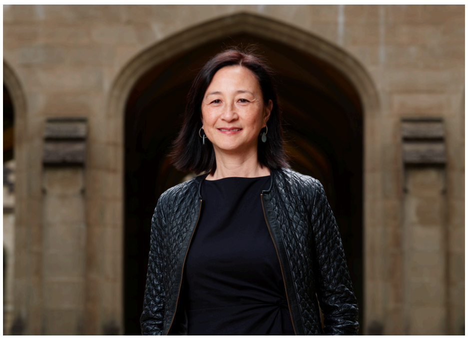
CRE Awarded Project Funding 2025

Investigator Name & Institute	Research Focus
Free Coulston (UoM)	Validation of the Partnership-focussed Principles-Driven Online co-Design (P-POD) Evaluation Survey.
Shiraz Badurdeen (MCRI)	Causal Machine Learning for Estimating Individualised Treatment Effects for Extremely Preterm Infants in the PLUSS Trial
Anjali Haikerwal (MCRI)	Impact of the COVID-19 pandemic on the mental health of mothers of infants born extremely preterm
Cassidy Du Berry (MCRI)	Barriers to and facilitators of the use of home oxygen therapy in infants with bronchopulmonary dysplasia: a caregiver perspective
Abbey Eeles (UoM)	Mindful Self-Compassion for Parents in the Neonatal Intensive Care Unit: A Consumer-Driven Feasibility Trial

CRE Awarded PhD Student Top-up scholarship 2025

Student Name & Institute	Research Focus
Gemma Duff (UoM)	To understand environmental influences on physical activity (PA) for children born preterm.
Zi Yan Ong (Monash)	Investigates executive function developmental trajectories from early childhood to adulthood and its neurobiological correlates in individuals born very preterm (VP).
Fatma Lelik (Monash)	Utilising two very important studies -SurPre & VICS2022, we aim to identify meaningful risk and protective factors for later cognitive, socio-emotional, language functioning in those born very preterm/very low birth weight.
Susan Fehring (UoM)	Investigate early intervention for very preterm infants delivered by physiotherapists and occupational therapists in the first year of life.
Luke Howlin (MCRI/UoM)	Long-term respiratory consequences of extreme prematurity within the context of evolving neonatal therapies.

PhD Highlights



Susan Fehring

BPhysio, SpecCertCR(Neuro), MPhysio

Hi, I'm Susan! I'm a neonatal and paediatric physiotherapist, mum to two fabulous young adults, an obsessive plant propagator and serial home renovator. After years of juggling my clinical career and family life, I've embarked on a mid-life sabbatical gap year (or three!) to dive into full-time PhD studies.

Throughout my career, delivery of great care that meets the needs of children and their families has always underpinned my clinical work. After more than a decade working at the Royal Children's Hospital in neurodevelopmental and complex healthcare programs, I had the opportunity to return to my subspeciality area of interest as a neonatal physiotherapist at Eastern Health. Alongside my work in the TEDI-Prem (Telehealth for Early Developmental Intervention for babies born very preterm) research study, I started to recognise the gap between what we as clinicians know, or want to deliver i.e. evidence-based practice, and what is actually delivered within available healthcare resources. Had I succeeded in delivering great evidence-based care? The jury is still undecided!

This led me to my PhD where my research aims to explore implementation of early developmental interventions for infants born very preterm, delivered by physiotherapists and occupational therapists during the first year of life. My first research study will describe the professional landscape in a national survey of physiotherapy and occupational therapy current practices. Looking forward I'm interested in understanding the perspectives of parents and clinicians, and I'll draw on current practices to explore how developmental interventions can be shaped and tailored to meet the needs of families.

I'm also excited to explore how my research findings can align with other EPIC research and ultimately lead to better care and outcomes for preterm infants and their families. I look forward to exploring how my research field of interest aligns with and contributes to EPIC research, and ultimately leads to better care and outcome for preterm infants and their families.

Dr Stacey Peart

BBNSc, MBBS, FRACP

Stacey is a Melbourne-based neonatologist and clinical researcher, with a keen interest in improving the care and outcomes for the most preterm infants and their families.

Her PhD is addressing under-represented cohorts in neonatal clinical trials, which has encompassed two large projects addressing different preterm populations.
The first of these was the Most Premature Babies Priority Setting Partnership (PSP), an international Perinatal Research Partnership (IMPACT) initiative in association with the James Lind Alliance. The PSP brought together people with lived experience and clinicians to jointly determine the most important areas for research for infants born before 25 weeks' gestation. The hope is that these findings can be used as a voice for advocacy by researchers and research funding bodies to implement studies that improve relevant and meaningful outcomes for the most preterm infants and their families.

Stacey's work has highlighted the need for greater representation of infants born before 25 weeks' gestation in the neonatal literature, and she hopes to continue international collaborative efforts to further work in this area. Stacey's second project has been the AIROPLANE Trial. This is a multicentre, cluster-randomized crossover trial conducted in 26 Australian maternity hospitals and recruiting over 1800 infants to compare 30% oxygen and 21% (air) oxygen for moderate-late preterm infants born 32 -35 weeks' gestation who receive respiratory support at birth. The trial has been completed with results to be presented soon! This is the first study to investigate initial supplemental oxygen in moderate-late preterm infants and will provide evidence for international resuscitation guidelines for this cohort.

Stacey looks forward to combining her experience in clinical trials, working with people with lived experience to help bridge the evidence gap and provide the best possible care to all infants born preterm.

Congratulation's to Dr. Kate Hodgson who received a 2025 Strategic Grant for Outstanding Women (SGOW) from Melbourne Medical School, Dr. Sam Axford for Best Overall Presentation at the RWH Student Symposium and Prof. Jeanie Cheong & Dr. Cassidy Du Berry for collaboration on a MRFF grant to support the BALLOON study, led by Curtin University. Congratulations to Prof. Brett Manley and team awarded the prestigious Australian Clinical Trials Alliance-Trial of the year 2025. Congratulations to Myness Ndambo, Dr. Amanda Kwong, Dr. Elyse Passmore, Dr. Abbey Eeles and Siân Slade for winning the Impact Health Catalyst award for 'MyoTrack' a solution aimed at preventing malaria reinfection among children under five years of age in Malawi.