ISSUE #4

EPIC Newsletter

August 2026

EPIC Moments You'll Want to Know About

This month's newsletter is all about connection. Across the EPIC community, we're seeing the power of partnership shape better outcomes for babies born preterm and their families.

Whether it's consumers influencing research priorities, clinicians translating evidence into practice, researchers answering critical questions, or communities improving health literacy, a common thread runs throughout this edition: meaningful impact happens when we get together. What matters to families, clinicians, researchers, educators and communities may bring different perspectives and priorities but each contributes valuable expertise and insight.

This edition is rich with stories from people who have helped shape the prematurity field. Associate Professor Rosemarie Boland shares reflections on a career dedicated to supporting babies and families beyond the NICU through some of life's most challenging transitions. Willow Boughton, offers insights into what it means to grow up preterm and her contributions helping shape the future of preterm research through the EPIC Lived Experience Network and the Guideline Development Group.

You'll find updates on the SurPre Model of Care, which is helping translate the 2024 Australian Guideline for Follow-up Care of Children Born Very Preterm into practice through a co-designed approach involving families, adults born preterm, clinicians and researchers.

We discuss findings on:

- Hyperglycaemia and hypernatraemia research
- Introducing the SHARE donor milk study
- Emerging results from the AIROPLANE trial

Our Program Highlight this edition features the Water Well Project, an inspiring initiative working to improve health literacy and access to trusted health information across Australia.

We're also excited to share the program for this year's Research Connection Conference where families, clinicians and researchers will come together to explore the transitions that shape the lives of children born preterm.

Our conference theme is particularly timely.

A recent UK study involving almost 16,000 children born before 32 weeks' gestation found that many children born very preterm experience challenges with school readiness and early educational attainment, reinforcing the importance of supporting families through these key transitions and strengthening collaboration across health, education and community services.

This focus on partnership is reflected more broadly across the research sector. The updated NHMRC Statement on Consumer and Community Involvement reflects a growing commitment to conducting research with consumers and communities through co-design, shared decision-making, inclusion and meaningful involvement across the research lifecycle.

Similar conversations are taking place internationally, with the International Association for Public Participation (IAP2) currently reviewing its Spectrum of Public Participation following extensive global consultation. The review reflects a broader shift towards recognising that better decisions, stronger partnerships and greater impact are achieved when diverse voices are meaningfully included.

For us this reinforces a principle at the heart of EPIC; meaningful progress happens when families, medical professionals, researchers and communities come together to learn from one another, share stories and knowledge while working towards a common goal.

Megan Morales
EPIC Project Coordinator

Spotlight on Rosemarie Boland: Bridging the Gap from NICU to Home

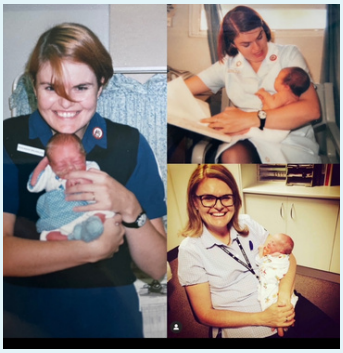
Thank you, A/Prof. Rosemarie Boland, for generously sharing your time and allowing us to celebrate your remarkable journey and contributions to the field.

Associate Professor Rosemarie Boland has dedicated her career to improving care for babies born early and supporting the families who love them. From her beginnings in midwifery to decades in neonatal intensive care, retrieval services, education and research, she found herself asking: "What happens next for families after leaving the NICU?" "I saw a real gap," Rose reflects. "Families spend weeks or months in NICU with constant support and attention then suddenly, they're home and expected to navigate everything on their own."

This insight led to the creation of Precious Care "Baby Safe" education programs. Designed to give parents practical, evidence-based guidance as they transition home. What began as small, in-person sessions has grown into nationally accessible resources, including online programs developed during COVID. At the heart of Rose's work is a deep commitment to empower families with information and confidence. She highlights the higher risks faced by preterm babies and the importance of education around safe sleep, early recognition of an unwell baby and baby first aid. "If I can help one parent make a safer decision at home, then that matters," she says. Alongside her research, clinical and education work, Rose has contributed to statewide policy and improvement efforts. Rose led the development of the Safer Care Victoria Extreme Prematurity Guideline for babies born at 22–24 weeks supporting clinicians and families with evidence-based guidance across care before, during and after birth, including both active and palliative approaches.

At its core is a commitment to shared decision-making with families, particularly within the "zone of parental discretion," where decisions are complex, deeply personal, and shaped by individual circumstances. Parent information sheets were co-designed with members of the newborn medicine CAG (currently LEN) -Parent Advisory Group at MCRI. Integration of clinical, research, and educational expertise reflects Rose's broader philosophy: that high-quality care must centre on the needs of babies, parents, and families both during NICU admission and after discharge.

Looking ahead, Rose is optimistic. She highlights Australia's strong collaborative research environment, and the impact of networks like EPIC in driving change. The preterm journey doesn't end at discharge. "It's two steps forward, one step back," she says. "And that journey continues long after NICU."



Rosemarie over the years

Willow at Ateez Concert

Introducing Willow Boughton

Born at 27 weeks and is now a young adult contributing her voice through the Lived Experience Network

I'm Willow, I was born at 27 weeks, weighing just 935 grams. After being transferred between hospitals. I received care at the Royal Women's Hospital, and later the NICU at the Royal Children's Hospital. My story is closely connected to Mena. Born at the same time. Our mums were side by side in the NICU. Mena had many complications like mine and sadly didn't survive; this is something my family has never forgotten. I come from a big family. Five of my eight siblings were also born premature, all before 32 weeks. I'm the second youngest and earliest born. Growing up, family responsibilities, social challenges and financial pressures made it difficult for me to access early intervention services.

I've experienced several health complications over the years and have been recently diagnosed with ADHD and Autism. I often wonder if this relates to being born preterm or other genetic or developmental factors. I am part of the original Victorian Infant Brain Study (VIBeS) and completed my 20-year follow-up. I value being involved in research. I connected with EPIC at the 2024 Research Connection Conference, and joined the Lived Experience Network. I'm part of the Guideline Development Group for adult follow-up care. I'm passionate about understanding growing up preterm and how it shapes long-term health. I love books, music, and live performances.

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

For me, it's the connections. Hearing parents' stories, and meeting other young adults born preterm, has been really meaningful especially given how little information there is about adulthood. I've loved learning about research. What's happening now, where it's heading, and how it it can improve outcomes for future premmies.

Looking back, what's one piece of advice you wish you had?

Get involved in the premmie space. Join groups, attend webinars, take part in research or training to build your understanding of prematurity and it's impacts. Many experiences especially around mental health or lung development can be overlooked or not fully understood. Building your health literacy and connecting with others with shared experiences can enrich your life. Put yourself out there you never know what you might gain.

Is there anything that feels difficult to say out loud, but important for people to hear*?*

Access to care is one of the biggest challenges for those with social and financial barriers outside of metropolitan areas. There is still limited awareness of the lifelong impacts of prematurity, and information, healthcare services and support can be inconsistent, especially in regional and rural communities. I've personally experienced situations where symptoms were dismissed or not recognised as being linked to my preterm birth. These experiences highlight the need for greater awareness, better recognition of the long-term effects of prematurity, and more consistent support for people born preterm as they grow into adulthood.

Research spotlight: Double Trouble? The Combined Impact of Hyperglycaemia and Hypernatraemia in Preterm Infants

With thanks from Associate Professor Gayatri Jape from the King Edward Memorial Hospital & The University of Western Australia.

Babies born very early (before 28 weeks) have a lot to adjust to after birth. Their bodies are still learning how to control important things like breathing, fluids, and nutrition, including blood sugar and salt (sodium) levels.

Two common issues doctors see in these premature babies are: (1) High blood sugar (hyperglycaemia) and (2) High sodium levels (hypernatraemia). Clinicians often worry about these early changes, especially in the first week, when babies are most fragile. Does these early imbalances affect how babies develop later in life?

What was this study about?

Fursule, et al. (2026) asked if extremely premature babies (< 28 weeks) develop high blood sugar, high sodium, or both in the first week after birth, does this affect their development at two years of age compared to babies with normal levels?

What did the study find?

The reassuring finding was that premature babies with high blood sugar, high sodium, or both did not have worse developmental outcomes at two years of age. In fact: Babies with high sodium levels did not show poorer developmental outcomes compared to others. The study was limited being a single-centre one and therefore difficult in determining cause and effect hence the need for further research across different settings.

Why is this important?

In the NICU, changes in blood sugar and sodium levels are common and can be worrying for both doctors and parents. This study helps understand that these early changes are often part of the baby's adjustment after birth and may not necessarily lead to long-term developmental problems.

What can parents take from this?

For parents, this study offers reassurance: (1) It is common for preterm babies to have fluctuations in blood tests early on (2) These may affect developmental outcomes at two years. Parents can still ask: "How are my baby's fluid and blood sugar levels being monitored?"

Key Message

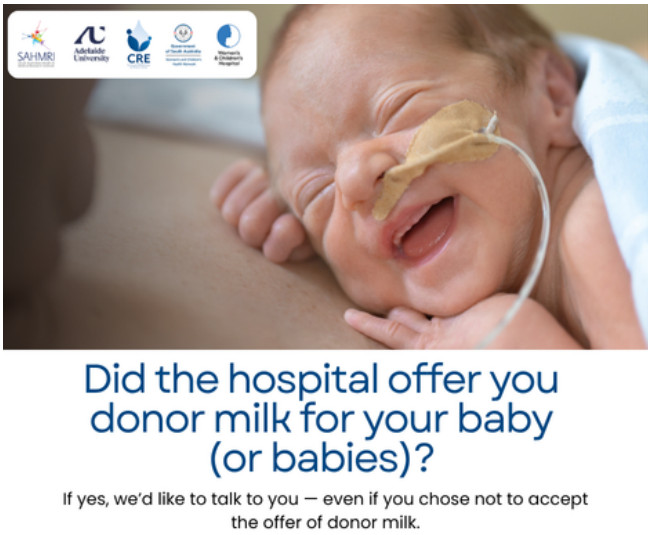
Early changes in blood sugar and sodium levels for extremely premature babies are common, and do not appear to affect long-term development. These results help us to understand how tiny babies adapt in their first days of life.

The SHARE Study: Supporting Donor Human Milk Access By Researching Families' Experiences

Written by Lilliana Drapaniotis, MRes student at Adelaide University and SAHMRI.

Prematurity can create many challenges for establishing breastfeeding. When a baby is born very early, and mother's own milk is in short supply or unavailable, families may be asked to decide whether to accept donor milk for their newborn.

Donor milk is breast milk donated by another mother to a milk bank, where it is screened, pasteurised, and distributed to hospitals for babies in need. In Australia, the Australian Red Cross Lifeblood's milk service (launched in 2018) supplies donor milk to hospitals across all states and territories. Donor milk is most commonly offered to families of babies born very preterm (less than 32 weeks' gestation) or with very low birthweight (under 1,500 grams).



Little is known about how families experience this offer, including what they understand, what they think, what they need, and how they make decisions during an often-overwhelming time.

The SHARE study is exploring Australian families' lived experiences of being offered donor milk. Through in-depth interviews with parents who have accepted or declined donor milk, the study aims to understand how these conversations happen in practice, what information families need, and how they ultimately make their choice.

The findings will help ensure every family feels genuinely informed and supported, whatever they decide.

This research is being led by Lilliana Drapaniotis, supervised by Prof Alice Rumbold, Dr Emily Shepherd and Prof Barbara Masser.

It's part of the ongoing work at SAHMRI Women and Kids, supported by the NHMRC-funded CRE in Human Milk Nutrition for Preterm Infants.

Lilliana Drapaniotis

If donor milk was offered for your baby and you'd like to share your experience, please click the link here

Rethinking Oxygen at Birth: Insights from the AIROPLANE Trial

Insights captured with thanks to Dr. Louise Owen and the AIROPLANE team.

The AIROPLANE trial is a large Australian study looking at how to best support the breathing of preterm babies after birth. It compares outcomes starting with room air (21% O2) versus slightly higher oxygen levels (30% O2). The findings will help guide future care, giving clinicians clearer evidence to support babies.

What are the key findings from the trial, and what do they mean for how care is delivered in the delivery room or NICU?

The trial did not find a difference between groups in the need for support on leaving the birth room. However, it did show that babies who started with the higher oxygen level had fewer stabilisation treatments at birth and had less need for later breathing support, after admission to the newborn nursery.

How might these findings influence future guidelines, standards of care, or decision-making in neonatal practice?

International bodies regularly review evidence on oxygen use at birth. Before the trial, both oxygen levels were already in use across Australian hospitals, with no clear agreement in international guidelines. In the most recent guidelines (2025) the ILCOR (International Liaison Committee on Resuscitation) stated that there was not enough evidence to make any recommendation for oxygen at birth for babies born at 32 to 35 weeks of pregnancy. We anticipate that the evidence generated will take the guesswork out of deciding what oxygen level to start with when using breathing support at birth.

How were families and lived experience contributors involved in the trial, and what value did their input bring to both the process and the outcomes?

Lived experience contributors from the Newborn Medicine CRE Consumer Advisory Group (now the LEN) were involved in the AIROPLANE trial from the beginning. Their insights informed study processes, including waived consent, helping ensure the trial reflected families' needs and experiences. CAG contributors remained involved throughout as investigators, steering committee members, and in developing materials, including the parent information video ensuring the study remained acceptable and relevant to families.

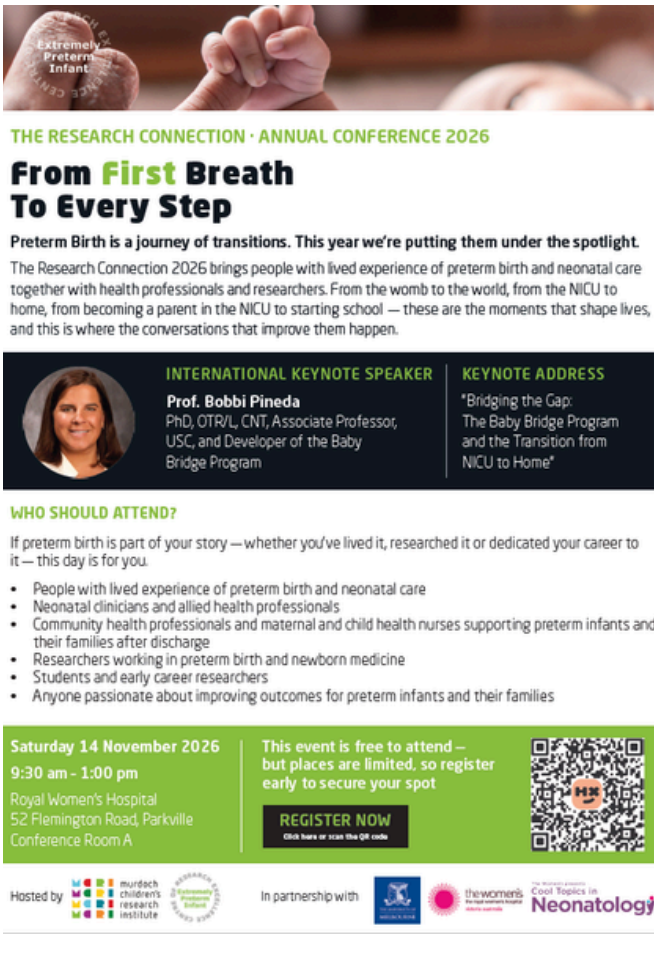
Taken together, what do TORPIDO 30/60 and the emerging AIROPLANE findings tell us about how we should approach oxygen use for extremely preterm babies in the future?

Oxygen use in the delivery room is complex. Since 2010, some guidelines have recommended using air (21%) for all babies born after 35 weeks of pregnancy, others for all babies born after 32 weeks. However, recent studies have suggested there may be more to this story than previously thought. TORPIDO30/60 examined 30% vs 60% oxygen levels at birth. Babies in that study were younger than in AIROPLANE. TORPIDO babies were born before 29 weeks of pregnancy. However, both TORPIDO and AIROPLANE results suggest higher starting oxygen may reduce stabilisation needs at birth and improve early outcomes. Together, these studies challenge current assumptions and open the door to further research on optimal oxygen levels.

What were the biggest challenges in delivering this trial, and what does it reveal about the future of neonatal research?

AIROPLANE included nearly 2000 babies across 26 sites in Victoria and NSW (from over 5000 births). Studies of this scale come with significant logistical challenges. Including site start-up processes, training and education at every site, ensuring babies received the correct treatments, ensuring we captured data for every baby who received study treatments etc. Innovative approaches helped – like cluster randomisation, waived consent, and real-time data collection systems. We trained hundreds of clinicians, returning to sites every 3 to 6 months to deliver more training as clinicians moved between hospitals. Over 600 clinicians contributed to data collection.

The study highlighted broader challenges: governance requirements, data protection (cybersecurity), funding constraints, and we experienced some negative media attention which raised questions about how the public may view medical research in the newborn setting. Neonatal research is evolving, all newborns have the right to access best care and the newest treatments; they should all be given the opportunity to be involved in research. We recognise that the birth of a preterm baby is an enormously stressful time for families, and we need to balance the burden of placing additional decision-making on them, with the right for their child to join research that could benefit them. Newborn research should be embedded in routine care. Yet growing governance demands, administrative burden, and funding constraints continue to place challenges on reaching this goal.



The SurPre Model of Care

Written by Evi Muggli on behalf of the SurPre working group and research team.

After several years of co-design and development, the SurPre Model of Care is now being tested in practice across four Melbourne newborn follow-up clinics.

The Model was developed to support implementation of the 2024 Australian Guideline for Follow-up Care of Children Born Very Preterm and to provide a practical framework for developmental surveillance throughout the preschool years. Developed through an extensive co-design process involving families, adults born preterm, clinicians, researchers and service providers, the Model is underpinned by six guiding principles: family-focused care, continuity of care, access and equity, effective communication, integrated referral pathways, and feasibility and flexibility. To put these principles into practice, the Model uses a tiered approach to developmental surveillance. Children are allocated to one of three monitoring levels based on their developmental profile, with the intensity of follow-up adjusted over time as needs change. Children move between monitoring levels as their needs change, helping ensure that resources are directed to those most likely to benefit while maintaining ongoing surveillance for all children.

Between 2025 and 2028, the feasibility study will evaluate the acceptability, feasibility and costs of implementing the Model in routine clinical practice. Feedback from families and clinicians, alongside data on developmental outcomes and access to early intervention services, will help identify opportunities to refine and scale the Model.

A manuscript describing the co-design and development of the SurPre Model of Care is in preparation. Findings from the feasibility study will contribute important evidence on how best to deliver developmental follow-up care for children born extremely preterm and their families.

Sweet Afternoon Supporting Miracle Babies

Prakriti Koirala, Megan Morales, Tara Fitzgerald, Alyce Farrugia, Jeanie Cheong, Alicia Spittle, Loni Binstock, Gemma Duff, Sandra Kirolos & Susan Fehring

We were proud to support the Miracle Babies VIC High Tea fundraiser in July, helping raise awareness and funds for families navigating the challenges of premature and sick newborn care. Thank you to Alyse and the team for hosting such a special event to fund *Nurture*Groups.

PROGRAM HIGHLIGHT

Breaking Barriers in Health Literacy

A conversation with Dr Linny Phuong, Founder of the Water Well Project.

The Water Well Project

For Linny, the idea began long before medicine. The daughter of Vietnamese boat refugees, she grew up navigating the healthcare system alongside her parents, often acting as their interpreter. As a junior doctor, she began to see the same story repeat patients presenting with preventable conditions, often linked to language barriers and limited access to clear health information.

What is the Water Well Project, and how does it work?

The Water Well Project is an award-winning charity that strengthens health literacy for migrant, refugee and asylum seeker communities. Its delivers free, interactive, community-based health education sessions led by volunteer healthcare professionals.

How is this approach different from traditional health education?

Rather than positioning medical professionals as distant experts, Water Well creates informal, respectful spaces that encourage open, two-way conversations. “In many communities, medical professionals are seen as untouchable. We’re trying to break that down to share stories, laugh, and learn from each other.”

What challenges arise when delivering health information across cultures?

Working across diverse communities presents practical and ethical challenges. Some marginalised groups are harder to reach, often lacking central hubs and limited resources. Delivering accurate health information must be balanced with cultural and religious sensitivities. “You want people to be informed, but don’t want to offend or alienate anyone finding that balance is one of the hardest roles.” Over time, Water Well has developed a structured, co-designed approach while working with community partners to tailor communication and build trust. Safeguards include feedback channels, two facilitators per session, strong links with community leaders, and a clear focus on general (not individual) health advice.

What’s next?

The Water Well Project is increasingly focused on strengthening its impact through research and evaluation. As Linny reflects, “We’ve built those trusted relationships now we want to translate that into meaningful research and evidence.”

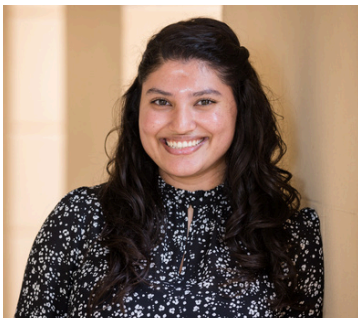
How could the EPIC CRE community get involved?

There are several opportunities to collaborate and contribute:

- Volunteering as a healthcare professional.
- Supporting community-informed research and co-design.
- Contributing to accessible, culturally responsive resources or donations are always welcome.

“There’s so much potential to work (with EPIC) especially around co-design and research that’s meaningful for communities.” Together, these efforts can strengthen how we engage with families and communities particularly those who are often hardest to reach.

PhD Highlights



Karen Mistry

Physiotherapist, DPhysio, BEXSs & PhD Candidate

Hi, I'm Karen, a physiotherapist, and I recently completed my PhD. I have worked clinically with children in education, health, and research settings for eight years. Early in my career, I was often referred children who had just started prep/kindergarten and were struggling with motor skills compared with their peers. At that stage, teachers and families often raised concerns and sought further assessment for the children. I did often wonder whether these children could have been recognised much earlier and benefited from intervention before reaching school age. This experience piqued my interest in research around early identification and lead me to completing the PhD.

My PhD, embedded within the PREBO-6 project, looked at whether brain scans taken soon after birth in very preterm babies could help identify which children may later develop motor difficulties. In my first paper (a systematic review), we collated the existing research on early neonatal MRI and later motor outcomes, and showed that early brain imaging had the potential to identify children at risk, although there was considerable variation in how studies measured and reported outcomes.

In my second paper, we found that MRI taken early after birth could identify those at risk of later motor difficulties at 6 years of age, just as well as scans taken closer to term age. We also found that early differences in brain development, particularly in regions involved in movement such as the cerebellum were strongly linked to later motor outcomes. Together, these findings suggested that we may be able to identify at-risk children while they are still in neonatal intensive care, opening a new window of opportunity for early interventions and allowing us to plan follow-up and support services for these babies sooner.

I am incredibly grateful to the children and families who participated in the study, my supervisors, the PREBO-6 study team, the Queensland Children's Hospital, and the University of Queensland. Completing my PhD has been a rewarding opportunity to combine my clinical experience with research that has the potential to improve outcomes for children born very preterm and their families.

Dr. Kate Rawnsley

BPhysio (Hons), MPhysio, PhD

I'm Kate. I am an early career researcher, paediatric physiotherapist and mum of three young children. My oldest daughter was born with a rare, genetic disorder and spent most of her first year of life in the Royal Children's Hospital. I unexpectedly became a 'hospital parent' in the workplace that I had farewelled mere weeks earlier when I excitedly began parental leave! The following year our family moved to a regional town. Our daughter, who was considered 'high-risk' for developmental delay, went from being fully supported with her medical and allied health team to sitting idle on waiting lists for many months, during a period that was crucial for her brain development. I was perplexed that our experience could be so vastly different, just two hours away from Melbourne. I realised I was in a unique position, with the combination of my professional and personal experience, to address the disparity in access to developmental services for families residing outside of metropolitan centres and those who have difficulty attending face-to-face consultation. This was the motivation for my thesis titled 'Early detection of developmental delay using remote assessment methods'. Coincidentally, 3 weeks into my PhD the first COVID-19 lock down occurred, catapulting telehealth and remote healthcare access into the spotlight.

My PhD completed in 2025 explored the agreement between telehealth and face-to-face delivery of a commonly used gross motor assessment for infants (the Alberta Infant Motor Scale) as well as parental acceptance of the telehealth assessment. The accuracy of parent-completed developmental screening questionnaires was investigated and clinicians' perspectives of telehealth in both high- and middle-income countries was explored (currently under review for publication). While, not without limitations, telehealth and parent-completed questionnaires offer an alternative to face-to-face consultation. improving access to developmental services in both clinical and research settings.

Looking forward, I hope to translate my thesis findings into practice supporting more children, in more places, to reach their potential. I have been so privileged and grateful to have been surrounded by the wealth of knowledge and support within EPIC and Paeds Co-LAB communities.

Congratulations Professor Katherine Lee who was awarded a 2026 NHMRC Investigator Grant. Congratulations to Associate Professor Gayatri Jape finalist in the 2026 Women of Colour in STEM Awards. Congratulations to Tugba Alarcon-Martinez on receiving RACP Foundation funding to study clinician stress during neonatal intubation. Congratulations Loni Binstock and Sonali Zanatta on their successful selection to participate in the Family Engagement in Research (FER) course. Congratulations to Abbey Eeles, Amanda Kwong and Elyse Passmore on their recent trip to Malawi in support of the MyoTrack project. Congratulations Megan Morales for being awarded a CSL Community Impact Scholarship to participate in the Melbourne Business School Emerging Social Purpose Leaders Program 2026.

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