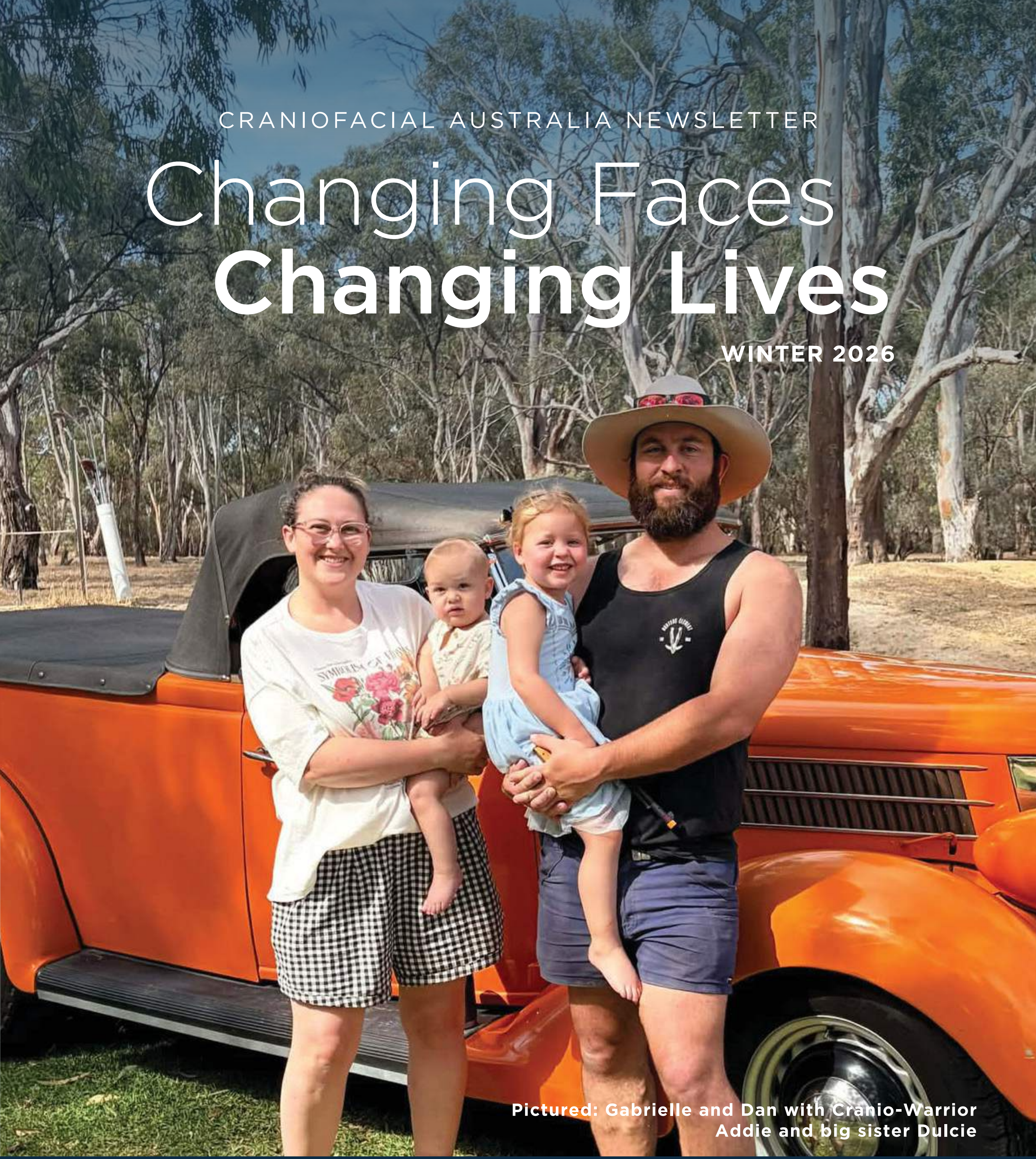
CRANIOFACIAL AUSTRALIA NEWSLETTER

Changing Faces
Changing Lives

WINTER 2026



Pictured: Gabrielle and Dan with Cranio-Warrior Addie and big sister Dulcie

Craniofacial Australia
Changing faces | Changing lives

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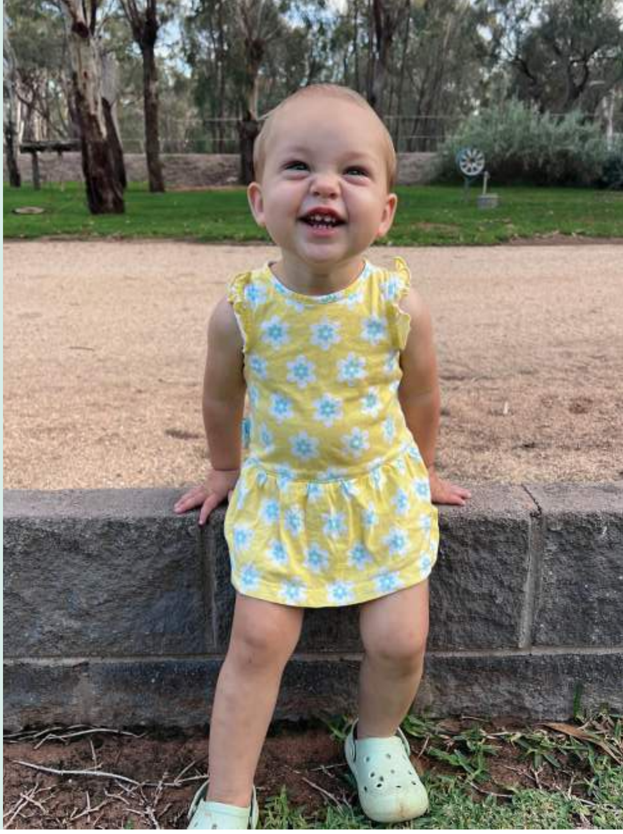
From Uncertainty to Strength

Adelaide's Brave Beginning



Through the eyes of Gabrielle and Dan, this is the story of their baby girl, Addie. A journey marked by uncertainty, resilience, and hope, as their family navigates a craniosynostosis diagnosis and life-changing surgery in her first year.

We welcomed our beautiful daughter, Adelaide (Addie), in October 2024. At just one week old, we noticed her fontanelle seemed unusually small, along with a ridge running from her forehead to the back of her head. Despite raising concerns early, we were reassured that she will "grow out of it".

By four months old, during a routine immunisation visit, a baby health nurse immediately recognised that something wasn't right and arranged a referral to the Royal Children's Hospital in Melbourne. After travelling four hours from regional NSW for our appointment, Addie was diagnosed with Sagittal Craniosynostosis, which would require surgery.

On the drive home, we began searching for support and found Craniofacial Australia. The care package we received, along with emotional and financial support, made an overwhelming time feel far less isolating.

After further scans and specialist appointments, we faced the anxious wait for surgery. With just two weeks' notice, Addie was scheduled for Total Cranial Vault Reconstruction in November.

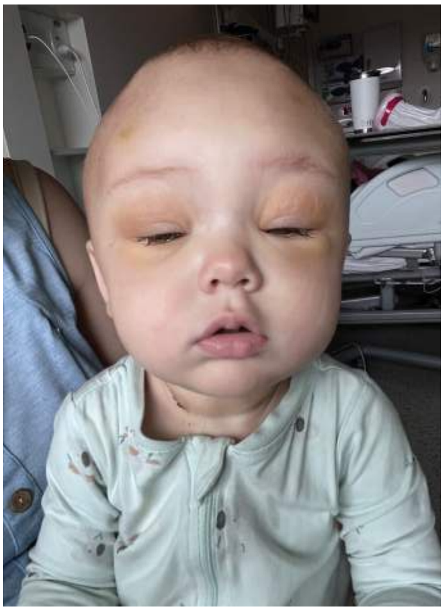
It was a long and difficult day, complications during surgery meant Addie was taken to ICU. We were finally met with her, showing swelling, tubes and wires. This was overwhelming to say the least. In the days that followed, both her eyes swelled shut, but throughout it all she remained incredibly brave, while charming everyone around her.

Just before discharge, one eye opened, and her bright, cheeky personality returned instantly. After five days in hospital, we finally brought her home to her very excited big sister.

Without the support of Craniofacial Australia, both financially and emotionally, our journey through Adelaide's diagnoses, surgery and recovery would have been far more traumatising and financially draining for us all.

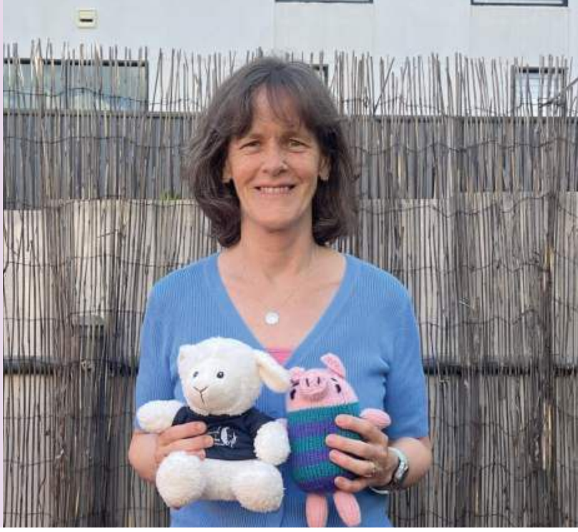
Now, five months post-surgery, Addie is thriving. Her hair has grown back and her scar is barely visible. You would never know what our brave girl has been through.

Addie's story is a powerful reminder that behind every donation is a family navigating the unknown. Your support this tax time helps ensure they're not doing it alone.



A Message from Lou

There's no such thing as a "typical" day in this role. Every family's journey is different. A cleft or craniofacial diagnosis can be overwhelming. For many families, it's the first time they've ever heard the term. Once they leave the doctor's office, they're often left feeling frightened, isolated, and unsure of what comes next.



I recently spoke with a family who had done everything right. They asked questions, organised care, even quarantined, only for their baby's surgery to be cancelled at the last minute due to illness. The emotional toll was immense. In these moments, families don't just need information. They need someone to listen, to reassure, and to walk alongside them through the uncertainty. That's where I can help and it's a privilege to do so.

Recently, I also connected families affected by less common craniofacial conditions, including Bicoronal Craniosynostosis and Pierre Robin sequence, helping them find comfort in shared experience.

Every day, I send Care Packs, connect families, and find solutions. But beyond the practical support, I show up to help families navigate the emotional challenges they face so they never feel like they're doing this alone.

Remember, I am here for families at any stage including when things are going well. We love receiving visits from friends and families when they are in Adelaide.

Thanks to your support, families have someone in their corner, a real person to guide them through the tough moments.

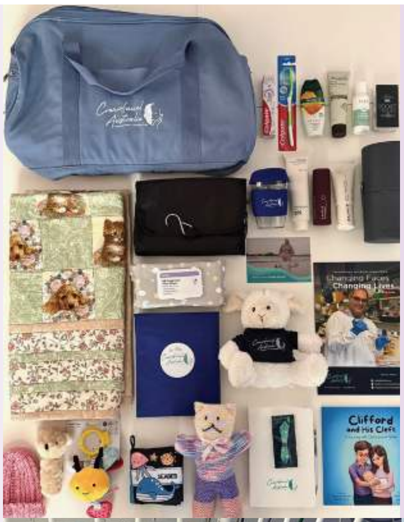
Lou McNeil
Family Support Coordinator

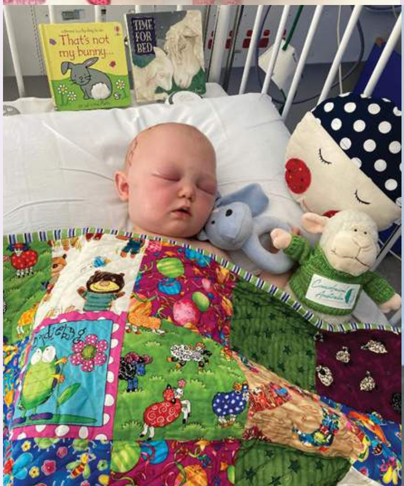
Wrapping Families in Care

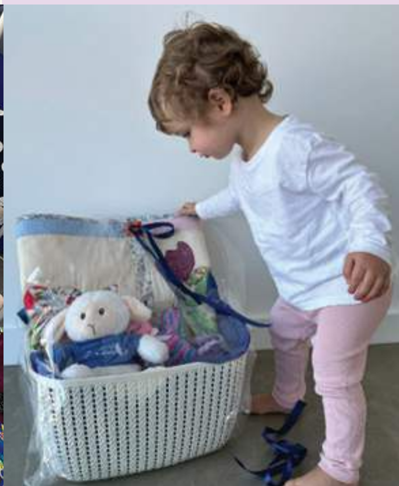
When hospital stays, treatment plans and surgery begin to feel overwhelming, even the smallest gestures of care can make a meaningful difference. In the past 12 months alone, we have delivered **71** Care Packs to families when they needed it most and provided financial assistance to **14** families.

"Thank You for the incredible care package we received prior to George's surgery in November 2025. We were so touched by the generosity and thoughtfulness of the package, and even the kind gifts for our other children. The hardest part for us was the wait in between the diagnosis and surgery, and to receive the package along with your lovely note was just like a warm hug of support."

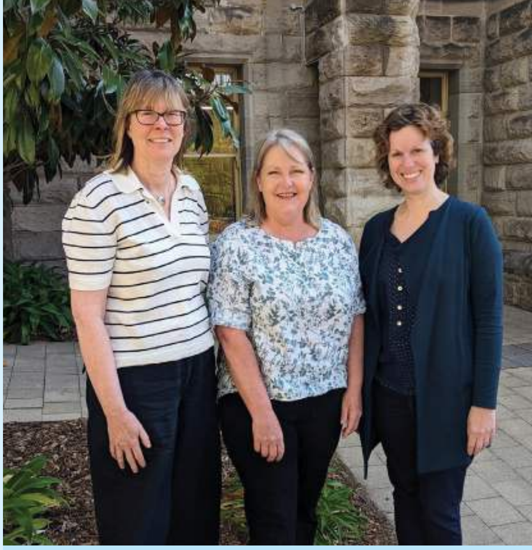
Wrap a family in care. Donate a care pack today.







Call for participants:
Help Shape What Comes Next



Adelaide University

'More than a diagnosis: Voices of those living with craniofacial conditions'

A/Prof Rachel Roberts, Dr Amanda Osborn, A/Prof Diana Dorstyn

Through one-on-one interviews, participants are invited to share their experiences of school, friendships, healthcare, identity, wellbeing, and navigating the world around them. By hearing directly from people with lived experience, this research will uncover insights that have never been captured in Australia before.

We are still actively seeking research participants and encourage you to share this opportunity within your networks.

Why this research matters: The findings will help shape more inclusive healthcare, guide practical resources for families, schools, and clinicians, and highlight gaps in care that too often go unseen. Most importantly, it ensures future services are designed with people with craniofacial conditions, not just for them.

Who can take part: Anyone aged 8 years and over with a craniofacial condition (excluding isolated clefts). For participants under 16, parent consent is required, with each child's comfort and wishes guiding their involvement.

To learn more or get involved:

Email:
amanda.osborn@adelaide.edu.au

Phone:
0439 854 092

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NEW RESEARCH ANNOUNCEMENT IN THE UK
Closing the Gap in Wide Cleft Palate Treatment

'Management of Wide Cleft Palate: A Systematic Review of Surgical and Multidisciplinary Approaches'

Prashan Kangesu - Plastic Surgery Registrar, Oxford UK, Lead Researcher

Ms Nitisha Narayan - Consultant Cleft Surgeon, Bristol UK, Supervisor

Mr Marc Swan - Consultant Cleft Surgeon, Oxford UK, Supervisor

Ms Amy Davies - Cleft Collective, Bristol UK, Research Coordinator & Statistician

This new research project, funded by Craniofacial Australia, aims to understand how "wide" cleft palate is defined worldwide and how surgeons in the UK measure and treat it.

Cleft palate is a condition present at birth where there is a gap in the roof of the mouth. This can make feeding difficult in babies and affect speech development as children grow. Surgery is usually performed early in life to close the gap and improve function, but some children may still need further treatment.

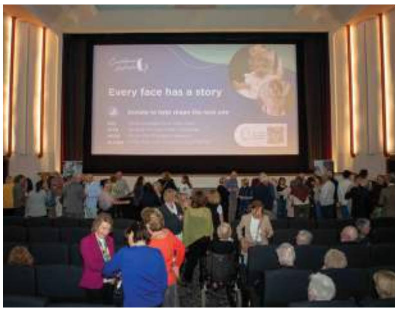
Wider cleft palates are more challenging to repair, yet there is no agreed definition of what makes a cleft "wide." There is also no clear guidance on how cleft width should be measured or how it should influence surgical technique.

The research team says **"We will do this by surveying UK cleft surgeons and reviewing all published research on the topic. The findings will help improve consistency in care and guide better treatment decisions, with the goal of improving outcomes for children born with cleft palate. Thank you to Craniofacial Australia and its supporters for their ongoing commitment to improving the lives of people affected by Cleft Lip and Palate".**

I Am Not My Face

In April, 160 guests attended a special preliminary screening at the Regal Theatre of 'I Am Not My Face', a powerful film by director and producer Benedict Anderson. The documentary explores the work and enduring legacy of Professor David David AC and the world-renowned Craniofacial Unit established in Adelaide in 1975.

Through deeply personal stories and expert insights, the film captures the lifelong journeys of individuals undergoing complex surgical care, highlighting their resilience in the face of stigma, bullying, and societal expectations.



View the full photo gallery at:
craniofacial.com.au/iamnotmyface

Pre-Loved Art Market

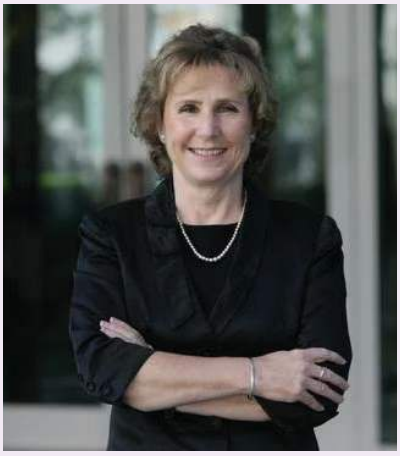
We're incredibly grateful to the wonderful team at Blackwood Rotary Club for organising the fantastic Pre-Loved Art Market in February in support of Craniofacial Australia. Thanks to this community fundraiser, over $5,000 was raised, vital funds that help us continue supporting families in our community. This generous effort enables us to provide care packs and financial assistance, invest in life-changing craniofacial research, and fund education and awareness initiatives. Partnerships like this play a critical role in helping us make a meaningful impact, both locally and nationally. We extend our sincere thanks to everyone involved at Blackwood Rotary Club.

Times are tough right now and we're looking for people to step forward.

If you've ever thought about running a fundraiser - whether it's a morning tea, community event, or challenge, now is the time. As an individual, in your workplace, school or club. We'd love to partner with you to raise funds and awareness for the cleft and craniofacial community, just as Blackwood Rotary Club have done.

Contact Meg, our friendly Marketing & Fundraising Coordinator:

E: fundraising@acmff.org.au
P: (08) 8267 4128

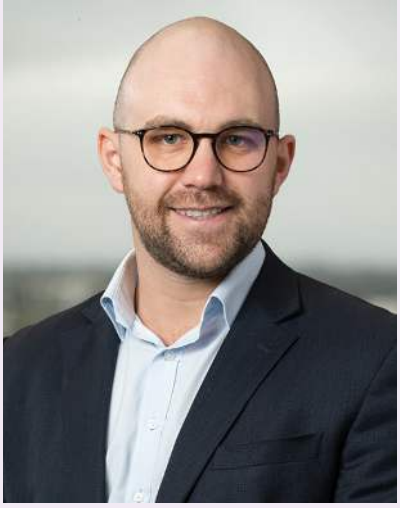


Welcoming Our New Board Members

We are delighted to welcome Isobel Redmond and Michael Davies to the Craniofacial Australia Board. Isobel brings a wealth of experience across law, public service, and leadership, having served as a respected parliamentarian and the first female leader of the South Australian Liberal Party.

Michael joins us with a strong background in finance and advisory through his role at PwC, along with a passion for community and strategic growth.

Together, their expertise and perspectives will further strengthen our governance and support our mission to create meaningful impact for individuals and families living with craniofacial conditions.



Turn Your Steps Into Support

Craniofacial Australia is part of some of Australia's biggest fun runs and we'd love for you to be part of them. Whether you're a seasoned runner, prefer a casual jog, or simply want to walk with friends and family, there's a place for everyone at the start line.

Each event is not only a chance to get active, connect with our community, and enjoy the atmosphere, but also an opportunity to make a real difference, helping raise vital funds and awareness for individuals and families living with cleft and craniofacial conditions.

HBF Run For A Reason

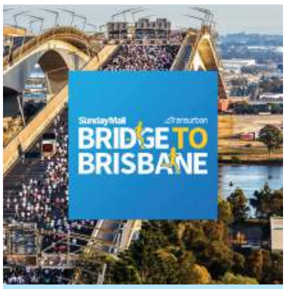
Perth
Sunday 24 May

Run Melbourne

Melbourne
Sunday 19 July

City 2 Surf

Sydney
Sunday 9 August



Bridge to Brisbane

Brisbane
Sunday
13 September

City-Bay

Adelaide
Sunday
20 September

Scan to register your participation

Thank You!

We extend our sincere thanks to our incredible community, generous donors, and valued partners for your ongoing support. Your kindness and commitment make everything we do possible, helping us provide care, fund vital research, and support individuals and families living with craniofacial conditions. Together, we are creating a future filled with greater understanding, connection, and hope.

A Message from the Chairman

For more than five decades, I have had the privilege of providing healthcare for children and families suffering from craniofacial anomalies. I have seen both their courage and the challenges they endure. While surgery can change lives, the journey extends far beyond the operating theatre. Through the generosity of our community, this ensures that we can continue to support the patients and their families via the multidisciplinary team with care and compassion, so no one faces this path alone.

David

Prof David David AC
Chairman