CRANIOFACIAL AUSTRALIA NEWSLETTER

Changing Faces **Changing Lives**

CHRISTMAS 2026



MAX'S JOURNEY
Through Mum Jorja's eyes

Craniofacial Australia
Changing faces | Changing lives

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“It’s such a privilege to be able to say, ‘We can help.’”

An update from Claire, Family Support Coordinator



Since returning from parental leave in July, it has been wonderful to reconnect with our cranio families. I’m continually inspired by the strength and positivity of the parents and children I have the privilege of supporting.

While I’ve been away, some things haven’t changed. Families are still receiving diagnoses with little information about what comes next. Parents are still travelling long distances for specialist treatment, often facing unexpected costs and last-minute changes. For every appointment or surgery, there is a family trying to navigate uncertainty.

For many families, finding support starts with connecting with other parents through online support groups. These communities provide such valuable connections and reassurance, and we want families to know that Craniofacial Australia is here to support them from the very beginning. We warmly encourage health professionals to refer families to us at the time of diagnosis, so they can access trusted information, practical guidance and emotional support as early as possible, rather than having to navigate those first uncertain steps alone.

Our new Resource Hub is an important step in bridging the information gaps, providing trusted guidance, practical resources and reassurance.

In recent months, I’ve supported a family whose last-minute hospital appointment change meant their flights almost doubled in price. Thankfully, we were able to provide financial assistance to cover their travel costs.

I’ve also helped a mum whose own surgery was cancelled just days before she was due to travel, shared resources with families anxious about upcoming procedures, and supported parents coming to terms with a late diagnosis.

Sometimes the most important support isn’t financial or practical. It’s simply being there to listen.

Recently, I spoke with a mum preparing her daughter for a third surgery. Even after everything they’ve already been through, the nerves and uncertainty don’t disappear. As her daughter grows older, helping her understand what lies ahead brings a whole new set of challenges.

These are the moments that remind me why our work matters.

Alongside this support, I’ve been sharing our new Resource Hub guides and working to make our Care Packs even more comforting, including introducing sensory toys from Jellystone Designs.

I’ll never take for granted the trust families place in me when they share their stories. Whether it’s helping with travel costs, finding the right information or simply being a reassuring voice on the other end of the phone, it’s a privilege to remind parents:

“I see you. I hear you. And you’re not alone.”

As we approach Christmas, I want to wish all our beautiful cranio families a very Merry Christmas and a happy, healthy New Year. I know this time of year can look different for every family, and for some, it may bring its own challenges. Whatever this season holds for you, I hope it brings moments of joy, connection and time together with those you love. Thank you for allowing me to be a small part of your journey. I look forward to supporting you in the year ahead.

Liebelt

Claire Liebelt
Family Support Coordinator

Christmas can be a busy time, but appointments, treatment and recovery don’t stop because it’s December. If your family has surgery or treatment coming up, please don’t wait until you’re struggling to reach out.

Contact Claire:
familysupport@acmff.org.au

EDUCATION

Kat Bray

Cleft Speech & Language Therapy Inaugural Fellow



We're delighted to introduce Adelaide-based speech pathologist Kat Bray, the first recipient of Craniofacial Australia's new Cleft Speech & Language Therapy Fellowship. Kat is undertaking a 12-month fellowship at University Hospitals Bristol in the UK.

She will gain advanced skills in assessing and treating the unique speech challenges faced by children born with cleft lip and palate, while contributing to important research.

Made possible through the generosity of our supporters, this exciting new fellowship will help bring specialist knowledge and expertise back to Australia, improving care and communication outcomes for children and families well into the future.

Scan to learn more about our Cleft Speech & Language Therapy Fellow, Kat Bray.



Dr Andrew Stirrup

Cleft Surgical Fellow

For Oral and Maxillofacial Surgeon Dr Andrew Stirrup, cleft surgery is about much more than repairing a physical difference. It's about giving children the opportunity to communicate confidently, build connections and thrive.

As Craniofacial Australia's newest Cleft Surgical Fellow, Andrew has embarked on a specialist training opportunity in Bristol, UK, where he'll work alongside experienced cleft surgeons and multidisciplinary teams.

His fellowship will deepen his surgical expertise and broaden his understanding of comprehensive cleft care, from childhood through to adulthood.

Scan to learn more about our Cleft Surgical Fellow, Dr Andrew Stirrup.

RESEARCH

Three new research projects for 2027

Our investment in craniofacial research is growing. In 2027, Craniofacial Australia will fund three new research projects exploring important questions in craniofacial care. From the genes involved in craniofacial conditions to new ways of rebuilding bone.



ADELAIDE UNIVERSITY

PROJECT NAME

More Than a Diagnosis

RESEARCH TEAM

Professor Rachel Roberts, Dr Amanda Osborn and Associate Professor Diana Dorstyn

What is it really like to live with a craniofacial condition?

Research funded by Craniofacial Australia is looking beyond diagnosis and surgery to better understand the experiences of people living with craniofacial conditions.

More than a diagnosis is exploring the voices and lived experiences of the craniofacial community.

Understanding the social, emotional and everyday experiences of patients can help shape better support throughout life.

See the research you're helping make possible:

MONASH UNIVERSITY

PROJECT NAME

Preclinical Evaluation of Craniofacial Bone Regeneration Implant Material in a Mini-pig Calvarial Defect Model

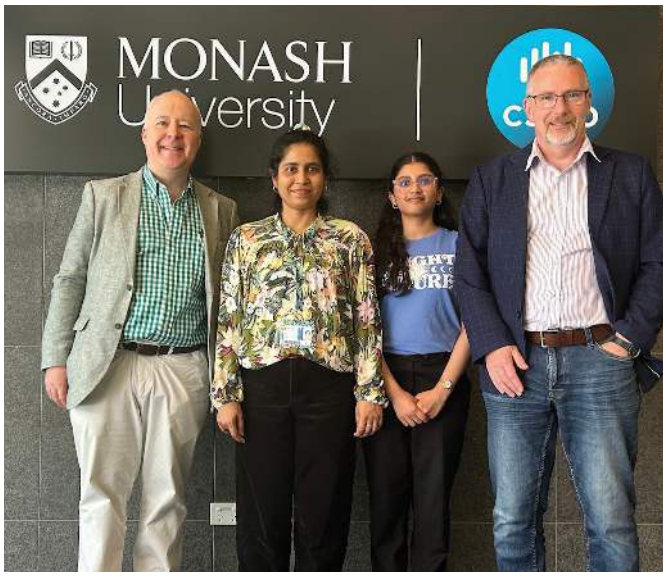
RESEARCH TEAM

Professor Neil Cameron, Dr Jessica Frith, Dr Romana Nasrin and Dr Stephen Goldie

Researchers at Monash University are developing a new way to help the body regenerate bone following craniofacial surgery.

The team has created a mouldable, resorbable scaffold designed to support new bone and blood vessels to grow within areas of missing or damaged skull bone. Early studies have shown promising results, and this project will take the next important step by testing the technology in a model that more closely reflects human craniofacial anatomy and healing.

In the longer term, the research could contribute to new approaches to craniofacial reconstruction and help overcome some of the limitations of current techniques.



LA TROBE UNIVERSITY

PROJECT NAME

Precise definition and targeting of Grhl2-dependent genes in palatal closure

RESEARCH TEAM

Associate Professor Sebastian Dworkin, Dr Jaeead Fuller, April Lewis, Zach Di Pastena and Maya Salama

Researchers at La Trobe University are investigating the genetics behind cleft palate.

Previous work by the team helped establish that mutations in a gene called Grhl2 can cause orofacial clefts. This project will investigate how this gene controls development of the palate and identify other genes involved in the process.

A better understanding of these genetic pathways could ultimately help improve genetic diagnosis and counselling for families and provide important foundations for future treatments.





ADELAIDE UNIVERSITY

PROJECT NAME

Discovering New Genetic Origins of Craniofacial Malformations

RESEARCH TEAM

Professor Quenten Schwarz and research team

Despite advances in genetic testing, many families affected by craniofacial conditions still don't receive a clear genetic diagnosis.

Researchers have identified a number of previously unknown genes that may be connected to craniofacial conditions. This project will investigate whether those genes play a role in the development of the face and skull.

Identifying more of the genes responsible for craniofacial conditions could help provide families with clearer answers, improve genetic counselling and better understand the likelihood of a condition occurring again in future pregnancies.

Looking to the future.

Supporting families today remains at the heart of what we do. But we also want to help change what craniofacial care could look like in the future.

By growing our investment in research, we can support discoveries that may lead to better understanding, earlier and more accurate diagnoses, improved treatments and better outcomes for generations to come.

Read more about our funded research projects:



Max's Story

"We never thought something like this would happen to us."

When Jorja and Nicholas welcomed their first baby, Max, they never imagined that within weeks they'd be facing the prospect of major surgery, thousands of kilometres from home. Here, Jorja shares the reality of their journey, and everything that comes with leaving home to get your child the care they need.

We're born and bred Territorians. We love the camping, fishing and laidback lifestyle of the Northern Territory, and you'd have a very hard time convincing us to leave.

When Max was born in October 2025, we were settling into life as first-time parents. During my pregnancy, we'd been told he had a larger-than-average head, but nobody seemed concerned. We just assumed he was going to be a big baby.

It wasn't until Max was four weeks old that a lactation consultant noticed something unusual about his head. She referred us to a paediatrician, reassuring us that it was probably nothing.

A week later, everything changed.

The paediatrician suspected Max had craniosynostosis, a condition where the bones of a baby's skull fuse too early. He would need further investigations, and eventually, surgery.

> "He will need surgery on his skull."
>
> Those words completely altered my brain chemistry and changed the trajectory of my motherhood journey.

I was in denial almost immediately. I remember thinking, "this can't be real, she has to be wrong." Tears filled my eyes as I tried to think of questions to ask.

Nothing compares to feeling so helpless for your own child.

Our lives were on hold.

LEAVING HOME FOR TREATMENT

There are no craniofacial surgeons in the Northern Territory, so we knew early on that we'd have to travel interstate for Max's treatment.

After exploring our options, we decided that cranial vault remodelling would be the best surgery for Max, and we were referred to the Women's and Children's Hospital in Adelaide.

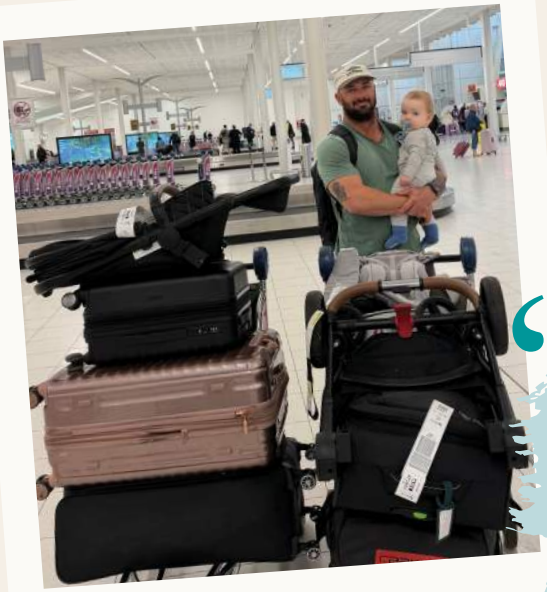
But for months, we had no idea when surgery would happen or how long we'd need to be away.

We couldn't make any big plans or commitments because we didn't know whether we'd be in Darwin or Adelaide.

And while we were prepared to do absolutely anything for Max, there was so much more to think about than the surgery itself.



A big journey for our little boy



"Just because we were going away didn't mean that the lawn would stop growing or the mortgage didn't need to be paid."

THE REALITIES OF TRAVELLING FOR TREATMENT

Imagine packing up your life for a month, taking your nine-month-old baby on his first flight and travelling thousands of kilometres to a city where you don't know anyone.

Max's surgery was scheduled for July, right in the middle of Adelaide's winter. Living in Darwin, we didn't own the warm clothes we'd need, let alone everything to keep a baby comfortable in the cold.

At home, you have the little things that make life with a baby easier. The rocking chair, the sterilising equipment, the toys, the familiar routines. Suddenly, we had to work out what we could fit into a few suitcases.

Then there were the expenses.

I was on maternity leave and Nicholas would be away from work, so we knew our income would be significantly reduced. We had flights to organise, accommodation to find, groceries and baby supplies to buy, and transport to and from the hospital. On long days, when all our attention was on Max, takeaway meals were often the easiest option. Those costs added up quickly.

And meanwhile, life back in Darwin didn't stop. Just because we were going away didn't mean that the lawn would stop growing or that the mortgage didn't need to be paid. We still had bills to pay, pets to care for and a property to maintain.

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THE DIFFERENCE SUPPORT MADE



It's difficult to explain just how overwhelming all of that feels when you're already worried about your child undergoing major surgery.

Thankfully, we didn't have to navigate everything alone.

Craniofacial Australia organised accommodation for us in Adelaide and helped with everyday living expenses. That meant we could concentrate on Max, rather than constantly worrying about how we were going to afford everything.

But the support went beyond financial assistance.

Our Family Support Coordinator was incredible. From the moment we reached out, we were met with genuine care and compassion. Even the smallest gestures meant so much, like a phone call to check on us after surgery or an offer to bring a coffee to the hospital.



Max's recovery has been remarkable. Aside from his adorable buzzcut and scar, you wouldn't know what he's been through. After receiving good news at his six-week post-operative review, it finally felt like we could breathe again. Even now, it's hard to believe we've made it through to the other side.

> "Because of Craniofacial Australia we didn't feel alone in our journey."
>
> - Jorja

This experience has changed us as parents and brought us closer together as a family. It's taught us strength and resilience we didn't know we had.

Looking back, my only regret is that we didn't reach out to Craniofacial Australia sooner. We never thought something like this would happen to us until it did.



Your Support Matters

Max's story is one of many. Every year, families across Australia face the emotional and financial pressures of travelling away from home for specialist craniofacial treatment.

This Christmas, we're sharing Max's story in the hope that more families can receive the care and support they need.

You can help make that possible. Please consider supporting our Christmas Appeal, enclosed.

Your Impact

60 families. One year of support.

Over the past financial year, Craniofacial Australia supported 60 families across Australia.

We sent **56 Care Packs**, provided **780 hours of family support**, and helped families facing the additional costs that can come with treatment.

None of this happens on its own. It's made possible by people who donate, fundraise, volunteer and choose to stand alongside cranio families.

This Christmas, you can help us be there for the next family who needs us.

Donate to the Christmas Appeal

Looking to the future

For many people, writing a Will is first and foremost about looking after the people they love. It can also be an opportunity to support a cause that has been important to them.

Gifts in Wills are our largest source of funding and play an incredibly important role in making our work possible.

After taking care of your family and loved ones, a gift to Craniofacial Australia, of any size, can help support cranio families and advance research well into the future.

Download your Gift in Wills Guide:



Farewell and thank you, Nicholas Pyne

After 20 years of dedicated service, Nicholas Pyne has retired from the Craniofacial Australia Board.

Throughout his two decades of service, Nicholas has brought invaluable experience, sound judgement and a steadfast commitment to our mission.

We sincerely thank Nicholas for his outstanding contribution and wish him all the very best for the future.

Community Fundraising



What a year for our community! From quiz nights and raffles to fun runs and workplace giving, our supporters found wonderful ways to get behind craniofacial families in 2026.



Quiz For a Cause

Cranio mum Tayla brought together 195 people in Queensland for an incredible quiz night, raising **$17,824**.

Pictured: Tayla Oliver and family, Quiz for a Cause.



Father's Day Raffle

Nina and the community at Style Philosophy Hair Studio SA raised more than **$300** with a Father's Day raffle.



Wear Purple for Leon

Katerina and Rod turned a time of uncertainty into action, raising awareness and more than **$7,000** in honour of their son Leon.

Pictured: Katerina, Rod & Leon



Westpac

Westpac contributed more than **$5,000** through its Car Park Initiative and Matched Giving Program, with special thanks to Cranio mum Rikki for championing our cause.



Walk for Cooper

Lisa invited her local community to walk throughout September in honour of Cooper, raising more than **$150**.



Zayelle

Thanks to Cranio mum Teegan, we were chosen as Zayelle's Charity of the Month, with $1 from every sale donated to Craniofacial Australia



City2Surf

Our Cranio Warriors took on Sydney's City2Surf, raising an amazing **$3,784.**



HBF Run for a Reason

Mum Sarah hit the pavement in honour of Cranio Warrior Zoe at HBF Run for a Reason, proudly raising **$2,374** for craniofacial families.



City-Bay Fun Run

This September, 44 runners and walkers came together for Team Cranio at Adelaide's City-Bay, **raising $7,037 from 118 donations.** Thank you to everyone who ran, walked, fundraised, donated and cheered Team Cranio on. Bring on 2027!

Over the past year, we've seen more people than ever stepping up to fundraise for us, bringing friends, families, workplaces and entire communities together. To everyone who has taken part in community fundraising, thank you. community fundraising is a vital part of what allows us to keep showing up for cranio families. You're helping build something we hope will only continue to grow.

If you've been thinking about doing a little something for Craniofacial Australia, perhaps 2027 is your year! We'd love to have you involved!

Contact Us

fundraising@acmff.org.au

craniofacial.com.au/fundraising

Scan to explore how to get involved:

RESOURCE HUB

Heading to hospital? Start here.



Trusted information.
Practical support.
Every step of the way.

When your child is diagnosed with a craniofacial condition, the questions can feel endless. What happens next? How do we prepare for surgery? What should we expect during recovery? And how do we help our child navigate school, friendships and everyday life?

Sometimes, the most reassuring advice comes from someone who has already been there.

That's what makes Craniofacial Australia's new Resource Hub so valuable.

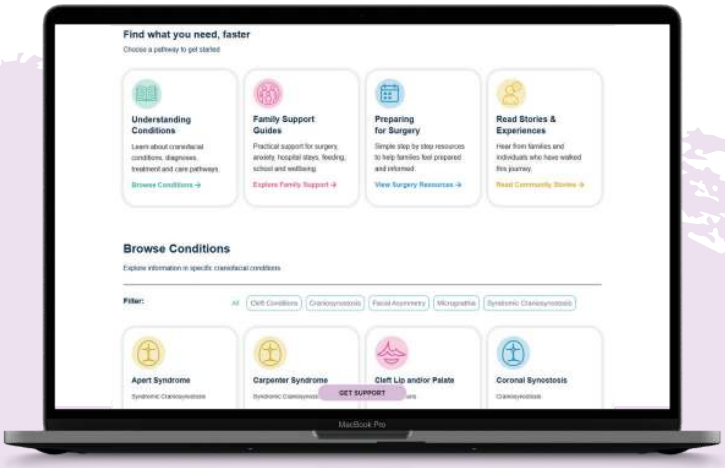
Developed through research involving families with firsthand experience of craniofacial conditions, the Hub brings together trusted information, practical guidance and insights from those who have walked this path themselves.

These are more than just information sheets. They're resources shaped by real experiences, reflecting the questions families wish they'd known to ask, the challenges they hadn't anticipated and the little things that can make a big difference.

From preparing for surgery and managing anxiety around hospital stays to navigating school, supporting siblings and caring for your own wellbeing, the Hub addresses the everyday realities of life with a craniofacial condition.

Families can also explore information about specific conditions and read personal stories from others who understand the journey firsthand.

It's knowledge informed by research, shaped by lived experience and shared to help the next family feel a little less alone.



Explore the Resource Hub

Scan the QR code to discover practical guides, trusted information and real stories from families who have been there.