

CRANIOFACIAL AUSTRALIA NEWSLETTER

# Changing Faces Changing Lives






SPRING 2024

PICTURED: HARRY VIDAL,  
CRANIOFACIAL AUSTRALIA FUNDRAISER



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# Harry's Mighty Heart

It's official! Harry and his faithful Clydesdale horses Henry and George have wrapped up their mighty fundraising trek. Clocking up over 1,150km, the formidable team started in Morgan (South Australia) and finished in Cunnamulla (Queensland) with an incredible fundraising tally of \$9,196.

Harry's Mighty Trek connected locals and raised awareness and funds to help those doing it tough in the craniofacial community. With this funding, we are empowered to continue our mission so that with diagnosis, there is also support, information, and better outcomes.

We gratefully acknowledge the generosity of the local community and countless small business owners who went above and beyond to support Harry's campaign. There were heart-warming stories of locals lending a helping hand, donating bales of hay for the horses, prizes for raffles, organising campfires and more.

**Above all, Harry's Mighty Trek was a mission characterised by purpose, empathy and camaraderie.**

## Did you know?

- Horse Henry lost a shoe in NSW. A most caring couple found it some 20km out of White Cliffs, brought it back to the local caravan park, and supported Harry with comfortable accommodation for the night. The following day, Henry's shoe was put back on by skilled local by the name of Matt.
- Harry's Facebook Group - "Harry's on a new adventure" - accumulated 499 members during the course of his travels!



### *Heartwarming Messages from the locals:*

"Hi there I met you on the road today at the water-crossing. Henry and George were a highlight of our day. Safe travels"

"We so enjoyed meeting you Harry, George & Henry, along the road from Menindee. We felt very fortunate to catch you along the way in your charitable quest. All the very best for your safe travels across our beautiful country"

### *We gratefully acknowledge the following businesses and organisations for welcoming Harry:*

- Maidens Hotel, Menindee, NSW
- Wilcannia Golf Club, NSW
- White Cliffs Hotel, NSW
- Wanaaring Store and Caravan Park, NSW
- Royal Mail Hotel, Hungerford, QLD
- Eulo Queen Hotel, QLD
- Warrego Riverside Tourist Park, Cunnamulla, QLD
- Club Boutique Hotel, Cunnamulla, QLD
- Cunnamulla Fella Visitor Information Centre, QLD
- Charlotte Plains: Outback Hot Artesian Bathing and Camping

**THANK YOU HARRY, GEORGE & HENRY FOR YOUR GENEROUS HEARTS AND SERVICE TO THE CRANIOFACIAL COMMUNITY.**



# Vale Bianca

***Memoirist and poet Maya Angelou once said that spirit is an invisible force made visible in all life. If we only pay attention, we will discover people like Bianca Zocchi. A spirited and generous woman who was an advocate for our cause.***



## **Bianca broke down obstacles and dedicated her life to serving others.**

A woman ahead of her time, she was known among family and community as the woman who took care of things. That she did, ever reliably. Even in her retirement, she was a beacon of community service. Volunteering at her church and St. Raphael's Aged Care facility, engaging in heartfelt conversations, and reading to those in need. Her selflessness extended to Vinnies, where she volunteered, and to her role as a pastoral care worker at Queen Elizabeth Hospital. She supported numerous charities, contributed to cake stalls, knitted trauma teddies, and even assisted at elections.

Bianca's connection to Craniofacial Australia began following a visit to her husband Luciano's homeland of Croatia in the early 2000's. Young Leo, a local boy, caught her attention. Born with Goldenhar Syndrome, he captured her heart. She embraced a new mission and a very big one at that. Bianca had one person in mind who could change the course of Leo's life.

Bianca's tenacity led her to schedule a meeting with Professor David David AC, where she asked him to take Leo's case. He agreed. Incredibly, Bianca raised over \$66,000 to advance Leo's medical care. A broad cross-section of the Australian community contributed to bring Leo to Australia, including Italian Australians, Croatian Australians and many others. Bianca tirelessly rallied the local media, taking Leo's case to the radio and newspaper. Leo travelled to Australia to access specialised care from the world-renowned craniofacial team in Adelaide. Leo's condition was complex and required multiple surgeries.

Leo recalls that when he was young, people often stared at him and teased him. He didn't enjoy playing with other children because their taunts were the hardest to bear.

Four of Leo's 22 surgical procedures were conducted in Adelaide. On all four trips, Bianca opened her home to Leo and his mother, caring for them during those times. Her altruism and compassion were part of who she was. The transformation

was more than skin-deep. With care and support from people like his family and Bianca, Leo developed resilience and strength of character from a young age.

Leo fondly remembers her encouragement, sharing that Bianca was a special person who taught him a lot. She encouraged him to believe in himself, study hard, and be thankful for his strengths. For example, Bianca instilled in Leo





that he was intelligent, being able to talk two languages.

Today, Leo has completed a computer science degree at Rijeka University in Croatia. He has worked for a Dutch IT company and is currently employed as an Implementation Engineer focusing on data-related tasks.

Recently, Leo shared his sadness about Bianca's passing. He expressed deep gratitude to Bianca for helping his mother Lorena and him during their stays in Adelaide. He will always remember Bianca as a brave, intelligent, and kind-hearted person who taught him a great deal about managing life and

encouraging confidence within himself.

Bianca, we salute you and the gifts that you brought to the world. Gifts that run deeper than what is seen face to face. Your legacy will live on in those whose lives you touched.

**We gratefully acknowledge Bianca's family for sharing her story.**

**We thank Leo for being his wonderful self and helping us understand how like Bianca, we can all play a part in inspiring hope and dignity in others, while being a force for positive change.**

## New family accommodation partnership

**We are thrilled to announce our newest accommodation partner: Quest Apartment Hotels King William.**

As part of our Patient Support program, Quest King William is a "home away from home" for families travelling to Adelaide for craniofacial surgery and treatment. It gives families somewhere safe, secure, clean and welcoming to stay. The location is close to the hospital, public transport and food outlets. Families can comfortably access a kitchen, laundry facilities, living / dining area, free

WiFi internet and more. It's all these "little things" that make a difference at an already stressful time.

Our heartfelt thanks goes out to Adam Goult (Front Office Manager) and Sarah Kalisimeras (Business Development Manager) from Quest King William for their passion, belief in our cause and the people we serve.

Our first cranio family from interstate stayed the other week and we were thrilled when Mum "J" emailed us with wonderful feedback:

**"Thank you so much to the Foundation and you all. One happy boy (cranio-warrior) tonight."**



# You are not alone



When you apply for a Care Pack or Financial Assistance via our website, our Family Support Coordinator Claire will contact you and support you throughout your journey.



Whether you need someone to talk to, have a question, or require further support, we are here to help.

Pictured above is Claire with the items we include in our Care Packs. Each one is packed by Claire with love, care, and importantly, for the whole family.

## Did you know?

Each Care Pack is valued at \$120 (incl. postage) and is made up of purchased items (satchel, books, toys, etc) and donated items, including Jamie's famous Cranio Warrior Tees!

### ► Contact Claire:

E: [FamilySupport@acmff.org.au](mailto:FamilySupport@acmff.org.au)  
P: 0432 473 747

### ► Apply for a Care Pack:

[craniofacial.com.au/care-packs](http://craniofacial.com.au/care-packs)

### ► Apply for Financial Assistance:

[craniofacial.com.au/financial-assistance](http://craniofacial.com.au/financial-assistance)

## Who we've helped

In 2023/24, Craniofacial Australia experienced an increase in demand for support. We are pleased to share the latest snapshot of who we helped in 2023/24, detailing how we served the craniofacial community.



► \$70,407 spent on Financial Assistance

► 65 Care Packs sent to families

An increase of 16%



### ► Care Packs by State:

NSW: 19	TAS: 2
QLD: 10	VIC: 18
SA: 8	WA: 6

# Step up for our Cranio-Warriors



Did you know that Craniofacial Australia relies of different types of support? These include Community Fundraisers, Appeals, Grants, Gift in Wills, Regular Giving, and more.

When you run a Fundraiser for Craniofacial Australia, you are helping to create a better future for people with a craniofacial diagnosis.

Fundraisers are an invaluable part of our sustainability as a charity. If you are interested in holding your own fundraiser or have an idea for a fundraising event within your community, our friendly Fundraising team are here to support you all the way.

Email: [fundraising@acmff.org.au](mailto:fundraising@acmff.org.au)  
Phone: (08) 8267 4128



## *Some fundraising ideas*



Movie night at your local cinema



Fun Run / Challenge

Workplace morning tea



School fundraiser - bake sale, lamington drive, crazy hair day, etc



Quiz night with your friends and loved ones

***& more***

CRANIO WARRIOR  
SPOTLIGHT



# Maeve the Brave

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**At birth, Maeve was diagnosed with severe Hydrocephalus, a neurological disorder caused by an abnormal build-up of cerebrospinal fluid in the ventricles (cavities) deep within the brain.**

A VP shunt and Rickman reservoir were placed at 4 days of life to drain the fluid surrounding her brain. Mum Taylah recalls: “Maeve had an abnormal shaped head when

she was born and it got worse as time went on. When I questioned it, I was met with, “this is just her head shape because of the fluid and shunt placement”.

After being discharged, Maeve was rushed to emergency in respiratory distress on two separate occasions. Both times nothing was found to explain her symptoms.

Maeve was then put under general anaesthetic for ENT, Gastroenterology and Respiratory exploration. Maeve was brought back to PICU on a ventilator. Taylah was told by doctors that they didn't expect Maeve to pull through after they removed the ventilator. Maeve is a little fighter and pulled through.

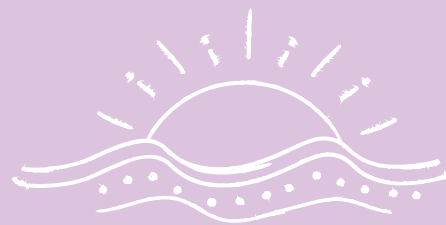
At Taylah's insistence, a referral was sent to the craniofacial team at Randwick Sydney Children's Hospital. A CT scan uncovered that Maeve's Lambdoid sutures had fused. Professor Chris Forrest explained that Maeve would require multiple surgeries for this rare occurrence. Maeve's surgery for Lambdoid Craniosynostosis is scheduled for November 2024.

Mum Taylah explains: “**With surgery approaching fast, it scares me what my 11 month-old daughter is going to go through. I just hope that this helps with all the symptoms she endures on a daily basis.**”

Taylah and Maeve, we stand alongside you as you step into the next stage of treatment. On behalf of the craniofacial community, thank you for bravely sharing your story.



# From Pakistan to Australia



**Staff at Craniofacial Australia were overjoyed to reunite with Mariam, who once again visited us from Pakistan.**

Adelaide is a bit like a second home for Mariam and her family. All of her major treatment has taken place in Adelaide. She came for the next stage of her treatment plan, reconstructive craniofacial surgery.

Mariam is in the skilled hands and care of Oral and Maxillofacial/ Craniofacial Surgeon and Board Member, Dr Ben Grave.

Mariam's care and treatment is possible thanks to you - our compassionate community.



*Mariam with the Craniofacial Australia team at our Melbourne Street office*



## STAFF PROFILE

**We welcome Kerri Jones, our new Marketing & Fundraising Coordinator.**

Kerri has worked in various sales and marketing roles throughout her career and recently decided to take the leap into a more fulfilling and meaningful role.

Kerri says, "I am excited to work with a talented and empathetic Team and Board, where together

we can use our strengths to help our craniofacial patients and their families."

Away from work, Kerri is a self-confessed "crazy cat lady", with four beautiful rescue cats. She also upcycles furniture and loves decorating her home, spending time in her tropical garden that she planted from scratch. Kerri also loves a refreshing green juice and has no interest in ever trying coffee.



# NEW RESEARCH ANNOUNCEMENT

Assoc. Prof. Quenten Schwarz  
University of South Australia



**We once again welcome Associate Professor Quenten Schwarz, whose new research project, commencing August 2024, aims to uncover the molecular mechanisms regulating normal jaw growth.**

Assoc. Prof. Schwarz' previous research uncovered that dietary supplements given to pregnant mothers can alter how the cranial skeleton of their babies grow. Remarkably, in some situations they found that these dietary changes can lessen the impact of genetic defects that lead to smaller jaws during pregnancy.

The results for this previous funding were used as preliminary data for the newly funded research project and are being written up in manuscript for submission this year.

## SUMMARY

Mandibular hypoplasia is a common congenital malformation with limited treatment options that necessitate major reconstructive surgery. While life-saving, these interventions result in a major burden of care, with long-term outcomes often below expectation.

Genetic defects have been defined in a small number of cases (i.e. TCOF mutations in Treacher Collins), however, the underlying biological mechanisms leading to jaw defects remain unknown in most cases and stand as a major area of unmet medical need.

## WHY THIS RESEARCH MATTERS

Assoc. Prof. Schwarz's work intends to uncover the molecular mechanisms regulating normal jaw growth and further identify chondrocyte death as a new biological origin of mandibular hypoplasia which will provide patients and families with answers to why they have been affected.

## ANTICIPATED OUTCOMES

This new knowledge is expected to provide the necessary information for development of diagnostics, predictive testing, preventative interventions and therapeutic strategies to complement existing surgical interventions to enhance jaw growth post-natally.

### Did you know?

Craniofacial Australia spent \$235,061 in 2023/24 on funding ground-breaking research projects.



## **Research Opportunity**

**Were you or a child you care for diagnosed with craniofacial microsomia\*?**

**\*The CARE study considers craniofacial microsomia to include hemifacial microsomia, Goldenhar syndrome, OAVS, and microtia**

**We want to know how craniofacial microsomia has impacted your life!**

**Participation includes completing a one-time online survey.**

**Your answers will be used anonymously to inform future care.**

**Visit [www.thecarestudy.org](http://www.thecarestudy.org) to learn more or scan the QR code below.**

**This study is currently open to residents of the USA, Canada, UK, New Zealand, and Australia.**



**The principal researchers for this study are Dr. Carrie Heike at Seattle Children's and Dr. Nicola Stock at the University of the West of England, Bristol, UK**



## **Did you know?**

Craniofacial microsomia (also known as hemifacial microsomia) is the second most common craniofacial condition after cleft lip and palate. It usually presents as facial asymmetry, and can affect the ears, jaw, and potentially cause eating and breathing difficulties.

# 40<sup>TH</sup> ANNIVERSARY GALA LUNCH

Please join us for a once-in-a-lifetime celebration, at our 40th Anniversary Gala Lunch. We will enjoy a 3-course meal, guest speakers, music, auctions, raffles and more at the Wolf Blass "The Man" Event Centre, overlooking the manicured grounds of the Morphettville Racecourse.

**When:** Sunday 20 October 2024

**Where:** Wolf Blass "The Man" Event Centre, Morphettville Racecourse, 79 Morphett Road, Morphettville, SA

**Time:** 12pm - 4pm

**Cost:** \$160pp / \$1,600 table of 10

All welcome, please invite your family and friends.  
Secure your tickets online:  
[craniofacial.com.au](http://craniofacial.com.au) or scan QR code.



We are also seeking sponsors and auction prize donations.  
Email [fundraising@acmff.org.au](mailto:fundraising@acmff.org.au) or call (08) 8267 4128 if you can assist.



**Proceeds proudly support programs for the craniofacial community.**