

Craniofacial Australia



Newsletter

Craniofacial Australia welcomes a new Partnership with Mantra Group.

Affordable convenient accommodation for the many patients who visit the ACFU and need to stay during surgery has been an ongoing issue.

As part of our solution Craniofacial Australia and the Mantra Group are proud to announce our new partnership. This exciting opportunity will provide family accommodation located at the West End of Hindley Street and about seven minutes walk from the new

Royal Adelaide Hospital.

Continued Page 2



BreakFree Adelaide

Sponsor Thank You

Once again our Platinum Sponsor Refined Real Estate proved that they really do live by their mantra:

“At Refined Real Estate, we are very community minded. We are committed in supporting local charities, not only via monetary donations, but also through involvement with events, donating items and providing Auctioneering services.”

Craniofacial Australia would like to thank our Platinum Sponsor, Refined Real Estate for their generous donation in 2017 of \$10,000 presented to our CEO Mr Bob Snewin at their recent Christmas event. This brings the total donated by Refined Real Estate and their staff to \$20,000 in the last 2 years.



REFINED REAL ESTATE PRINCIPAL MR VICTOR VELGUSH, WIFE SANDRA & CEO OF CRANIOFACIAL AUSTRALIA BOB SNEWIN, PRESENTING THEIR DONATION OF \$10,000

Inside this month's newsletter

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Craniofacial Australia is a registered charity (CCP2573 supporting the Australian Craniofacial Unit through patient care, family support, education, training & research

Phone 08 8267 4128
Fax 08 8267 5154

226 Melbourne Street North Adelaide SA 5006
www.craniofacial.com.au



Welcome to the Mantra Group

The BreakFree Adelaide offers patients:

Studio, 1 bedroom and 2 bedroom apartment option; each includes fully equipped kitchen and laundry facilities. This is ideal for the families who require accommodation during their stay here in Adelaide from a few days to a few weeks at a time.

The apartments were refurbished about 12 months ago, with new soft furnishings and appliances.

Craniofacial patients will be able to access discount rates from April 2018.

BreakFree^e



BreakFree Adelaide



BreakFree Adelaide
offer a range of Studio, 1 & 2 Bedroom Apartments



Changes to our Licence Number

Under new rules aimed to streamline reporting and eliminate duplication for Charities that are registered with the Australian Charities and Not-for -Profits Commission (ACNC), our licence number to collect money and provide entertainment for the purpose of fundraising has changed.

Our new licence number is CCP2573.

Eventually when all the states and territories come on line this number will replace all the different licence numbers we have in states where we fundraise, including our South Australian number CCP653.

You may notice this number change on our promotional materials, so we thought we'd let you know why. Same charity – different number

CEO Message

We are now well into the New Year and if like me, I keep wondering how fast the years come & go as well all seem busier in our life and commitments. Currently the Staff is planning our function and events calendar for this year and into the future. As with everything their planning is crucial in the very competitive not for profit charity sector & identifying the need to present varying fund raising opportunities. The Foundation this year will also be concentrating on attracting a new demographic to support our cause.

Whilst we always acknowledge the wonderful supporters we have now, attracting new people to the Foundation is important at all times.

We are deeply indebted to our Ambassadors and volunteers who work so conscientiously to assist the Foundation; their work in our Office or at functions is greatly appreciated. Sponsors, Ambassadors and volunteers are the life blood of any not for profit organization and the Foundation thanks and salutes them for their outstanding efforts and assistance.

I personally would like to congratulate Professor David as being awarded the “2018 South Australian of the Year” and ultimately being nominated for the prestigious position of “Australian of the Year.” As the Foundation Chairman he is fantastic to work with and his futuristic thinking for the betterment of this organization is awesome.

I also send best wishes to all our members and supporters from Professor David and the Staff of ACMFF.

Kind regards

Bob Snewin
CEO



From our CEO Bob Snewin



Patient Updates | Anh Tuan's Piano Performance

What a wonderful update about Anh Tuan

His mother wrote to the Unit recently and we are delighted to inform you that Anh Tuan was selected to play at the opening ceremony of the National Music Academy.

Minh Pham, Anh mother, from Vietnam wrote:

“Our family are happy to inform you that our son Anh Tuan has been selected as top 5 student to the Jazz Piano field at the Vietnam National Academy of Music. That result is due to countless support from CFF and other volunteers during his medical treatment.

After the hand surgery from Australia Anh Tuan used his finger rhythmically on the keyboard, creating more soulful sounds, helping him more confident in pursuing his music passion.

At the moment, Anh Tuan's health is good, only one obstacle is that he still does not have teeth . That makes him have to eat puree food and hardly to pronounce while talking with other people. There is not any hospital or medical center in Vietnam are being able to fix these problems for him. Our family are trying to help him to improve these problems as much as possible so he could make his dream come true.

We wish to have another chance to come back to Australia for his check up so that he could be more confident to integrate into community and lead his life more meaningful.”

Many thanks
Sincerely
Minh Pham

Please take a moment to view the video via the link below: It is truly inspirational.

<http://www.dailymotion.com/video/x622xgq>



Anh performs at the opening ceremony of the National Music Academy



Patient Updates - Grace & Joyce Tan

It is always wonderful and exciting when the Foundation receives updates about patients treated by Professor David and the Team at the Unit. This edition we are featuring a few of those for you.

Grace & Joyce Tan, currently live in Malaysia and they wrote to Professor David with this update:

“Hello Professor I am Joyce Tan here, the Malaysian twins with Crouzon syndrome. We would like to share a little update about us.

Back in July last year, Grace and I were interviewed and featured in our local newspapers by both The Star and SinChew Daily.”

Living life to their fullest follow Grace & Joyce’s story here:
<http://www.sinchew.com.my/node/1667062>



Joyce teaches year 5 students at Taylor’s International School Kuala Lumpur



Grace teaches year 4 students at Taylor’s International School, Puchong.

Patient Updates - Ari Nakkour



A EMAIL UPDATE FROM JESS NAKKOUR

“Ari is under the care of Prof David and the team at ACFU. We first saw Prof when he was 4 months old as soon as Prof saw Ari he told us there was more than one fusion and following a second CT scan was diagnosed with right coronal, metopic and bilateral squamosal fusions. Ari had a CVR and FOA in March 2016 when he was 5 months old. Ari’s condition is non-syndromic at this stage but we recently found out his sagittal suture has fused so are headed back to Adelaide soon.

Ari is doing beautifully despite this. Following his surgery he became this happy little guy and he hasn’t stopped making us laugh since. He even learnt to sit the day he was discharged from hospital. Ari is now an adventurous and fun 2 year old. We are forever grateful that we travelled to Adelaide to give Ari the best care possible and Prof is our hero.”



Thank you to our Sponsors 2017

Craniofacial Australia values the sponsors who have assisted the Foundation over the years. In December 2017, we decided it was time to thank them back.

We held a BBQ dinner for them at Partridge House and those who could attend provided wonderful feedback such as:

“It was nice that a charity actually acknowledged our support”

It is important to recognise the contribution that sponsors make to any charity. Without them, many of the wonderful items donated for our events would not be available to raise much needed funds for the patients and their families.

Thank you to all who assisted us in 2017 and we look forward to working with you again and to new sponsors who might wish to join us in 2018.

if you would like to become a sponsor please contact Sharon at:

sponsorship@acmff.org.au



**Refined Real Estate,
Victor Velgush
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**Refined Real Estate, Alison Hockney Sorbet,
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Tracy Bell, Blue Raine**

Welcome Natalie Munson

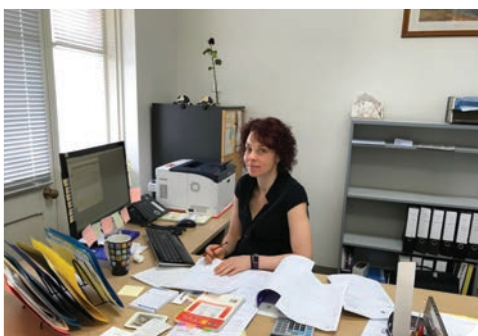
On behalf of Professor David, our Board and CEO we welcome Ms Natalie Munson, Group Accountant to the Foundation.

Natalie replaces Ms Pia Rossi who left us at the end of 2017.

Natalie will be undertaking this role 3 days per week:

Natalie's contact details are n.munson@acmff.org.au

Welcome Natalie we look forward to working with you.



Research Update

In July 2016, with assistance provided by a generous grant from the Apex Foundation, a team comprising researchers from the University of Adelaide & the Australian Craniofacial Unit commenced their research project into The Cognitive, Behavioural and Psychological Outcomes following Unoperated Metopic Synostosis.

Metopic synostosis is the premature fusion of the cranial (skull) suture **that runs down the middle of the forehead. It normally fuses within the first year of life.** However, when it fuses too early, the front of the head appears narrow with a ridge running down the middle. The resulting head shape is known as trigonocephaly.

The team involved in this project are:

Dr Amanda Osborne, Associate Professor Rachel Roberts, Professor Jane Mathias, Professor Peter Anderson, and Mr Walter Flapper.

To date the research project has involved a thorough literature review, which has clearly shown a trend towards unoperated patients having worse outcomes than their peers in intellectual, behavioural and **psychological outcomes. This is significant as it indicates the need for** ongoing monitoring and support of such patients.

The second part of the project involves the assessment of the intellectual & psychological function of patients with unoperated metopic synostosis. There are a number of patients under the care of the **Australian Craniofacial Unit with this condition; a significant proportion** has not undergone surgery and we are following their progress. To date, **23 such patients have been assessed and the findings from this initial group** are being analysed currently. The researchers hope to have some useful and interesting data from these patients in the next report.

Thus far the findings from the literature review have been submitted to the Journal of Paediatrics and shall also be presented at the Australasian Society for the Study of Brain Impairment 41st Annual Conference 2018.

Many thanks must go to the Apex Foundation as grants such as theirs allow research into important conditions such as this, which will ultimately result in improved patient management and care.

Mr Walter Flapper FRACS (Plast.) MA Surg (Craniofacial)
Consultant, Australian Craniofacial Unit



Save the Date

Adelaide Cup Brunch
Monday
12 March 2018

Luck of the Irish
Saturday
17 March 2018

Derby Day
Saturday 12 May 2018

CRANIOFACIAL AUSTRALIA ADELAIDE CUP BRUNCH

TICKETS ONLY \$15* PER PERSON

ADELAIDE CUP BRUNCH

WHERE 12.03.18 9AM - 11.30
TEN22 BOUTIQUE VENUE 1022 SOUTH RD EDWARDSTOWN ENQUIRIES 8267 4128
ONLY 120 SEATS AVAILABLE *BF APPLIES

BOOK ONLINE AT: [HTTPS://WWW.EVENTBRITE.COM/E/ADELAIDE-CUP-BRUNCH-TICKETS-42514019577?AFF=ES2](https://www.eventbrite.com/e/adelaide-cup-brunch-tickets-42514019577?aff=ES2)

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CRANIOFACIAL AUSTRALIA

PRIZES FOR BEST DRESSED

IRISH MENU

TICKETS \$70*

ST. PATRICK'S DAY PARTY

SATURDAY MARCH 17TH

1:00PM - 5:00PM

COCKTAIL SPECIALS
IRISH DANCERS

FIND THE LUCKY GOLD COIN & WIN A FREE COCKTAIL

COOPERS ALEHOUSE 360 MAIN NORTH ROAD BLAIR ATHOL

BOOKINGS EVENTBRITE.COM.AU | *BOOKING FEE APPLIES

CRANIOFACIAL AUSTRALIA IS A REGISTERED CHARITY CCP2573. SUPPORTING THE THE AUSTRALIAN CRANIOFACIAL UNIT THROUGH PATIENT CARE, FAMILY SUPPORT, EDUCATION, TRAINING & RESEARCH.

BOOKINGS NOW OPEN

MAKE SURE YOU SECURE YOUR PLACE

www.eventbrite.com.au

Save the Date



I WOULD LIKE TO MAKE A DONATION

Title: _____ First name: _____ Surname: _____

Company: _____

Address: _____

Post Code: _____ Phone No: _____

Email: _____

Please find enclosed my donation to ACMFF \$ _____

Method of payment (Please tick boxes): CHEQUE

Or

Please debit my credit card as follows:

Credit card type: VISA MASTERCARD

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Card expiry date: _____/_____/_____ CCV: _____ Signature: _____

Please send me more information on:

- Events
- Becoming A Member
- Please add me to your mailing list
- Please **remove** me from your mailing list
- Bequests



Complete form and return to:
Craniofacial Australia
PO Box 1138
NORTH ADELAIDE SA 5006



Phone: 8267 4128
(All donations over \$2 are tax deductible)





SPOT THE DIFFERENCE

Easter Word Search



- | | | | |
|--------|--------|----------|----------|
| eggs | spring | hunt | gift |
| bunny | April | candy | sun |
| rabbit | Sunday | vacation | duckling |
| chick | basket | lamb | holiday |

Color me in to win

For chance to win a Easter Basket filled with wonderful Easter treats simply color in the picture and send your entry to:



Color me in to win

PO Box 1138 North Adelaide SA 5006

Entries close March 20th 2018

HAPPY EASTER



PLATINUM SPONSOR



UNSURPASSED VIEWS AND LUXURY PRESENTED BY REFINED REAL ESTATE
EOI Closing Tuesday 20th of March at 1pm (USP)



LIGHTS CAMERA ACTION!
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Proudly positioned overlooking prestigious Penfolds Winery.

Superbly positioned on a large 911m2 allotment (approx.) set amongst established landscaped gardens, this striking and luxurious home is guaranteed to excite you.

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JAZZ IN THE GARDEN JAMES MORRISON & THE AUSTRALIAN ARMY BAND



Presented by
Craniofacial Australia

**VIP
GARDEN PASS**
Only 50 Passes
available
Be quick
\$150
per ticket

Craniofacial Australia presents:
Jazz in the Garden
Featuring James Morrison
& The Australian Army Band Adelaide, Jazz Ensemble

VIP GARDEN PASS
Want to be part of the VIP Garden
Tickets \$150 per person*
Sit back and relax in comfort for the afternoon
Your ticket entitles you to entry to the Event & our VIP Garden including
fully catered food & beverage from 1pm - 6pm
18+ Entry to VIP Garden
Tickets available at Oztix
<http://tickets.oztix.com.au/?Event=83495>
Only 50 Passes available - Be quick
*Booking Fee Applies

**Meet &
Greet with
James Morrison**
in our private bar and
photo opportunity
\$170 per ticket

MEET & GREET
Would you like to meet James Morrison?
You now have the chance to be part of the Meet & Greet
Only 30 pax available and these will sell fast.
This ticket entitles you to entry to the event, Meet & Greet with James Morrison
in our private bar and photo opportunity
All proceeds go to Craniofacial Australia
Tickets are \$170.00 per person*
Bookings Oztix
<http://tickets.oztix.com.au/?Event=83495>
*Booking fee applies



HOLDFAST BAY
proudly supported by
The City of Holdfast Bay

**ENTRY
\$70***

GENERAL ADMISSION
Sunday 25th February 2018
Partridge House Glenelg
Gates open 12 Noon
Kicks of @ 1:00 pm - 6:00 pm
Food & Beverage available for purchase on site
Bring your picnic blanket or comfy chair
Tickets Adults \$70 pp*
Children 10-16 \$10 each*
Children under 10 free when accompanied by a paying adult
*Booking fee applies
Tickets on sale at Oztix
<http://tickets.oztix.com.au/?Event=83495>

Contact for further details Craniofacial Australia 8267 4128
website: craniofacial.com.au



Buy tickets online at www.oztix.com.au
*plus booking fee

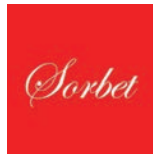
Thank you to our Sponsors

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SCARPANTONI
PREMIUM WINES OF MARGARET VALLEY



If you are interested in becoming a sponsor please contact Sharon at sponsorship@acmff.org.au

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