

# Craniofacial Australia Newsletter



## 1 Man, 1 Wagon, 2 Horses & A Dog !

Harry Vidal is undertaking a journey of a lifetime. Treking over 1500km from Murray Bridge to Lightning Ridge in NSW. Harry approached our CEO Bob Snewin in March and layed out his plan to raise funds whilst carrying out a life long ambition. After a BBQ breakfast hosted by the Rotary Club of Mobilong, Harry and his Clydesdales George & Henry departed Murray Bridge on April 11th.

ABC National Radio is covering Harry along the way and the townsfolk of the districts he has travelled have opened up their hearts, homes and wallets to help Harry raise \$10,450 so far. You can make a donation to Harry's Trek by direct deposit at any Westpac Bank . Continued on page 2.....

Account Name: Harry's Trek

BSB 030 010 ACCOUNT 229 802

## New Email

In keeping with the new website please note our new general enquiries email address is [info@acmff.org.au](mailto:info@acmff.org.au).

**The old email address [cranio@acmff.org.au](mailto:cranio@acmff.org.au) will no longer be in operation from June 1st, 2016.**

## New Website

[www.craniofacial.com.au](http://www.craniofacial.com.au) has recently been revitalised. Keep up to date with news, events, projects & what is happening at Craniofacial Australia.



Andrea  
Ogier  
Ambassador of  
the Month

Meet South Australia's frist recipient of plastic surgery to correct her severe birth defect [continued page 3.....](#)

## It's Tax Time

Don't forget to make your donation in time for the end of financial year. You can do so by filling in the form located on Page 12 in this newsletter

## Inside this month's newsletter

**Research project - Walter Flapper updates us on his latest project**

**Take a look at our new website : [www.craniofacial.com.au](http://www.craniofacial.com.au)**

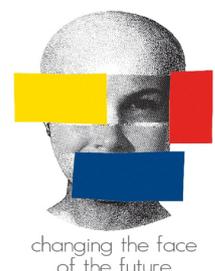
**Bequest Book - How do I arrange a bequest?**

**Tax Time -Donate before June 30th to claim your deduction**

Craniofacial Australia is a registered charity (CCP653) 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](http://www.craniofacial.com.au)





# Professor David

It is part of the ACMFF Charter to provide funding for medical education and in accordance with this, Professor David conducts lectures and training clinics to various countries in South East Asia.

Professor David is pictured here during one of these recent visits in Jakarta with medical specialists and trainees.



## Murray Bridge to Lightning Ridge contin....

Harry is currently a third of the way into his journey. Visiting Mallee towns Lameroo, Pinnaroo, Mildura, Wentworth and Pooncarie, he has been touched by the generosity of those who live in the towns. Locals have not only donated money, but food and water for the horses George & Henry as well. Facebook followers are enjoying the pictures posted and the school children along the way are excited to have a visit from Harry.

Harry hopes to arrive in Lightning Ridge in August if all goes to plan. Follow Harry via the Facebook page <https://www.facebook.com/Harrys-Trek-1576664709316716/>.

If you would like to help Harry reach his goal, you can donate by calling our office on 8267 4128 or you may make a donation at any Westpac Bank (Harry'sTrek).



A visit to Pattinson Nursing Home was welcome as was Harry's surprise visits at Palinyewah Public School, Lady of Sacred Heart Merbein & Underbool Primary School



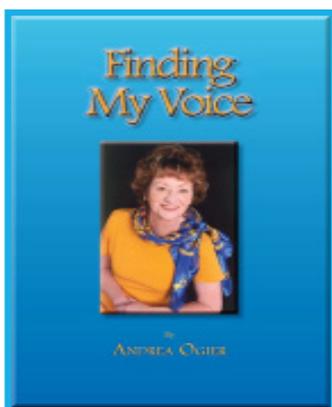
# How to leave a Bequest

A bequest to charity is probably one of the most considerate and worthwhile gifts we can leave. For most of us we don't want to think about death. Others plan for their's by preparing their will, outlining what they would like done with their estate when they are no longer here. Planning is an important factor when preparing your will. It can help alleviate stress for your relatives, particularly important if those you love are not clear about your wishes. Craniofacial Australia welcomes open discussion on how your bequest will be used to help our children of the future. Contact us on 8267 4128 for your free copy of our Bequest Book, which can assist you with any questions you may have at this difficult time. **If you are thinking about a charitable donation from your estate, please consider Craniofacial Australia**

## Changing Faces - Changing Lives

# Ambassador of the Month

Andrea Ogier was the first patient to undergo Plastic Surgery here in South Australia. Andrea has detailed her journey in a book she released in 2013, "Finding My Voice". Andrea regularly travels on speaking engagements and her story touches the heart of all those she meets. As a child, Andrea was born not only with a cleft palate, she also had a soft and hard palate deformity, which meant she didn't have a roof in her mouth. In her early years she was unable to speak, eat and drink in the way most of us know how. Despite all these obstacles Andrea overcame society's taunts and is a much in demand speaker on behalf of the Craniofacial Australia. To book Andrea as your next group speaker you can contact Andrea by either calling our office on 8267 4128 or emailing Andrea at [findingmyvoice44@gmail.com](mailto:findingmyvoice44@gmail.com)



Finding My Voice

## Membership

Membership pricing:

Adult \$27.50

Junior (under 16) \$5.50

Gold Life \$500

Membership runs from 1 July to 30 June

To join call our office on 8267 4128



## From our CEO Bob Snewin

For the Craniofacial Foundation, donations to our cause are vital to enable us to assist patients and parents, supply specialty operating equipment and fund ongoing research into craniofacial deformities.

The Australian Cranio-Maxillo Facial Foundation is authorized to issue fully tax deductible receipts for any donation whether it is cash, goods or services.

Here at the Foundation, we realize it has been a tough time for many people in our current economic climate. It has been a very difficult last 12 months in raising funds for the Craniofacial Foundation. If you are considering a donation to charity, I urge you to do so before the 30th of June so we can issue your donation receipt immediately, which you can claim on your taxation return.



# An exciting new research project to be conducted by the Australian Craniofacial Unit



Dr Walter Flapper

As one of its underlying principles, research is a significant component of the work undertaken by the Australian Craniofacial Unit. Indeed the Unit is proud to have contributed to a long history of world-leading projects, both clinical and laboratory-based. This continues with an exciting new project that we are currently undertaking in collaboration with the School of Psychology at the University of Adelaide.

Metopic synostosis is the premature fusion of the cranial 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 number of cases of metopic craniosynostosis presenting to craniofacial units around the world is increasing. Most are treated surgically, but there are a growing number of mild cases that are not. As yet, there are

no studies looking at the long term outcome in these children.

Our project will focus on those children with metopic synostosis, who have presented to the Australian Craniofacial Unit, but who have not had surgery as part of their management. In particular we will be looking at the cognitive (intellectual), mental health and behavioural outcomes in these children. We will also look at how the shape of the forehead changes over time in these cases. This will be the first study of its kind looking specifically at unoperated patients with metopic synostosis. It is envisaged that we will be enlisting at least 50 patients into this research project

Such a research project of this scale would of course be impossible without adequate funding. We are grateful for the generosity of the Foundation in sponsoring this project. We look forward to sharing the results in the future.

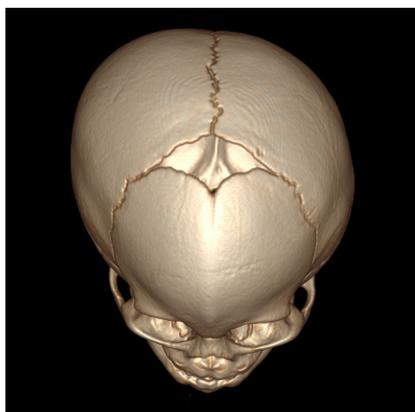


Figure 1: CT scan showing fused metopic suture

## Volunteers

Thinking of volunteering? If you have some time spare that you can contribute toward helping our foundation, then please complete the online form on our website and we will be in contact [www.craniofacial.com.au](http://www.craniofacial.com.au)

Sharon Forrester Jones (Craniofacial Ambassador) with Anna, Jan, Sarah & Ross who volunteer regularly at our functions



# Kate Hill Ward

For those who are not aware, the Kate Hill Ward is located in the Women's & Children's Hospital at North Adelaide.

Following a period of time in Intensive Care, Craniofacial patients spend their post-operative recovery time in Kate Hill Ward. The staff on Kate Hill Ward are specifically trained in Craniofacial Care, which give them a unique insight into the journey these patients undertake.

This year our Foundation has donated the following items to the ward. Some of the recent items include a breast pump which allows mums to express milk so that post-operative babies can feed. 9 Nylon skull models that surgeons use to plan surgery. Four (4) recliner chairs which enable parents to hold their child sooner post operatively allowing more comfort and a place to sleep by their child's side. In addition the Foundation keep Kate Hill Ward in supply of decorative comfortable arm splints to assist in the post-operative healing and soft spoons, so that patients can begin eating without risk of damaging fragile operative sites.



Matt Carter & Staff from Kate Hill Ward with some of the items donated by Craniofacial Australia

## Need to make a change to how you receive our Newsletter?

If you want to make changes to how you receive your newsletter please send an email to: [info@cranio.org.au](mailto:info@cranio.org.au) or call 8267 4128

Please email me the newsletter



Please post me a copy of the newsletter



Please remove me from your list



Dear Families & Patients, Craniofacial Australia welcomes patient feedback, stories & offers several avenues of support. If you would like to leave your details with us for updates please return the form below

NAME.....

ADDRESS.....

.....POST CODE.....

PHONE.....EMAIL.....

# Inaugural Derby Day Lunch

The inaugural Craniofacial Derby Day Lunch, held at the SAJC on May 14th had it all. Fashion, Food, Fillies and Fundraising was the order of the day and Adelaide's own Liza Emanuele showcased her latest designs for winter 2016, complimented by stunning men's wear from Joseph Uzumcu.

Guests enjoyed champagne on arrival kindly donated by Moët & Chandon. Sponsors Tiffany & Co kindly donated a beautiful piece from their 1837 collection for our raffle. Adelaide BMW provided the Major auction item and Refined Real Estate provided the must have wine lovers pack. For the politically minded we had 6 bottles of Parliamentary wine signed by the Premier and donated by Annabel Digance. Funds raised on the day will be used

toward patient research and education. There were prizes on offer for Best Dressed Hat with \$200 Voucher from Adelaide Hatters, Best Dressed Lady received a \$600 voucher from Liza Emanuele & Best Dressed Male received a \$150 Voucher from Joseph Uzumcu. Most Elegant lady of the day received the beautiful YSL gift pack and the Mystery Door Prize winner received a wonderful gift box set from Royce Chocolates. Thank you to all our sponsors on the day. A huge final shout out to all the professional staff at SAJC who ensured our guests were well looked after on the day.

See you all again in 2017

Reserve your seats now.

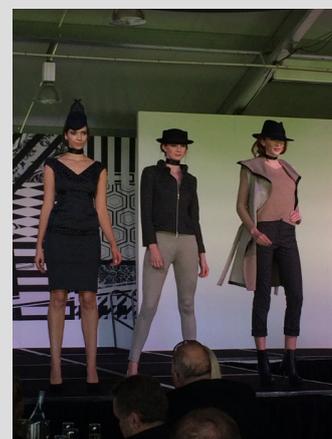


Liza & Finesse Models oblige photographers in front of the YSL media wall

## Derby Day MC Amelia Mulcahy



MC Amelia Mulcahy looking fabulous in her namesaked Liza Emanuele creation the "Amelia"



## NEW SOCIAL MEDIA

We are now on Instagram as well as Facebook & Twitter. Why not follow us and like our pages, all the while keeping up to date with the latest at Craniofacial Australia.





**At Refined Real Estate our goal is to make the process of selling, buying or renting a home smooth and rewarding for you. Our philosophy starts with good old-fashioned service.**

**Do unto others - the Golden Rule.**

**If you are looking at selling or renting in the near future, then give Refined Real Estate a call not only will you find yourself in very professional hands, you will also be helping Craniofacial Australia**

Victor Velgush, Principal of Refined Real Estate, & our auctioneer for Derby Day announced our new Platinum Partnership agreement for 2016/17. This partnership will see Refined Real Estate donate \$100 from each home they sell, \$200 from each signed rental referral & \$500 from each referred home sale at settlement.

Thank you Refined Real Estate for your generous contribution, we look forward to working with Victor and the team at Refined Real Estate over the coming year. Feel free to contact Victor & the team at Refined Real Estate. Phone: 8357 9001

Email: [reception@refined.com.au](mailto:reception@refined.com.au)

## **PROPERTY OF THE MONTH**



### **Private Peaceful Perfection**

**39 Waterfall Gully Road, Beaumont**

Welcome to a truly gorgeous attention dominating residence perched high on the hillside in this desirable Eastern suburbs location. Live every day amongst true beauty that only nature can offer, this gorgeous architecturally

designed home allows you to enjoy a convenient location amongst the wilderness, a truly enchanting location for your family to grow and thrive.

**Call Alexi Broikos**

**to arrange inspection**

**Mobile: 0408 080 375**

# Ryder's Story...Words from the heart by his dad Tory Wright



A routine visit from the Paediatrics to see how many toes and fingers that RJ has and of course we think nothing of it as this was our second child and we knew what was coming. That is until our Doctor calls for a second opinion when feeling RJ's skull for any abnormalities. You kind of worry a little but think nothing could possibly be wrong with such a perfect specimen as this? Could there?

The verdict Craniosynostosis or premature fusion of the skull... Instantly the wind is taken out of your sails and you worry whilst you wait for the referral from paediatrics to the right department for these answers. To this very day, I thank my lucky stars for where we live as having the experts on craniofacial procedures for Australia in Adelaide. This made life so much better for us all. Not only that but to have the world leading surgeon Professor David David at our disposal instilled such confidence in our journey that was yet to come.

Wow a 4 month old going under anaesthetics & having some of his skull removed. This is a scary thought but to be honest I couldn't have felt more confident with who was looking after Ryder and how. We were very much a part of the process rather than an after thought, we were included in all meetings & decisions as to how we would proceed. Surgery 27th Nov things go almost to plan with a small bleed but nothing out of the ordinary so it's off for recovery time in PICU. Seeing him for the first time post surgery was confronting but Ryder is my son so even though he was bandaged and had countless lines attached to him I thought he looked beautiful. The nurses and Professor briefed us as to how things had gone and what each line was for so we knew what was happening and we weren't kept in the dark. Ryder had terrors from the morphine which was not a nice way to see him, well that and the fact that each hour that passed his little eyes became more closed and more purple with bruising like he had been in some sort of infant gang fight. The more time passed the worse they got but we had been told this would happen. I tried to keep Ryder comfortable with a little toy monkey which I rubbed on his cheek to settle him throughout his time essentially being blind which lasted for around 48 hours.. Once Ryder could open his eyes again everything changed for the better. He instantly smiled being able to see again and oh dear more tears for a normally very unemotional daddy. Still a moment I will remember forever and definitely where you see leaps and bounds in recovery and progress for the better. Throughout the week in WCH we were visited regularly and honestly had the most beautiful nursing staff you could ever imagine having look after your baby on the ward . I believe one of the photo's we gave to the foundation certainly demonstrates this with Ryder gazing into one of the nurses eyes completely in love with her. A little later in the week his head bandage is removed to show some more confronting vision of the enormous amount of stitches in his little head and well let's just say a not really well shaped cranium. His head is still swollen and almost looks too heavy for him to hold up but he certainly seemed to have again turned a corner with his recovery again and all just within a week. Yes he is fragile and yes he is a baby but you see an amazing show of strength from somebody so apparently helpless in our eyes. His journey since his surgery has been amazing and his fighting qualities show more and more each day with quite the stubborn personality. Yes there are lot's of appointments and follow ups but those have also had us thanking Craniofacial legend Professor David David every time we see him. Thankful for his skills when we see new children in his offices waiting for appointments knowing that they too are going to be ok. This whole entire process is scary for sure but when you are in the hands of this amazing surgical team and support staff who do this day in day out you can set your mind at ease and let them get on with what they do better than anyone else in the world. We are so lucky to have the world leaders here to help our children through adversity as well as us as parents who need one less thing to worry about in life should something like this occur. I personally can't thank the team enough for making our gorgeous boy even more gorgeous.

Thank you Professor and your team and to all the staff at WCH who make our lives easier when it's not easy at all



# CINEMA CLUB OFFER 2 MOVIES FOR THE PRICE OF 1

June

August

**Craniofacial Australia\* & Adelaide Combined Lodges**



**Tickets only \$19 for 2 Movies**

At the Mitcham Cinema  
119 Belair Rd, Torrens Park

Another Great **Double Movie Night**  
**Sunday 19th June, 2016 @ 6pm**





**MONEY MONSTER**  
Crime/Drama  
Starring: Julia Roberts, George Clooney  
In the real-time, high stakes thriller Money Monster, financial TV host Lee Gates (George Clooney) and his producer Patty (Julia Roberts) are put in an explosive situation when an irate investor (Jack O'Connell) takes over their studio.



**ALICE THROUGH THE LOOKING GLASS** Adventure/  
Fantasy : Starring Johnny Depp, Anne Hathaway  
Alice returns to the whimsical world of Wonderland and travels back in time to save the Mad Hatter.

Australian Cranio-Maxillo Facial Foundation trading as Craniofacial Australia CCP653. Supporting the work of The Australian Craniofacial Unit through patient care, education and research. PO Box 1138, North Adelaide, South Australia 5006.

Tickets only \$19 each  
Phone Chris on 8267 4128  
or email:  
[cranio@acmf.org.au](mailto:cranio@acmf.org.au)  
[www.craniofacial.com.au](http://www.craniofacial.com.au)

**Craniofacial Australia\* & Adelaide Combined Lodges**



**Tickets only \$19 for 2 Movies**

At the Piccadilly Cinema  
181 O'Connell St. North Adelaide

Another Great **Double Movie Night**  
**Sunday 7th August, 2016 @ 6pm**





**Jason Bourne**  
Action/Thriller: Stars Matt Damon, Tommy Lee Jones, Julia Stiles  
Several years after his disappearance at the conclusion of The Bourne Ultimatum, Jason Bourne unexpectedly resurfaces at a time when the world is faced with unprecedented instability. Jason Bourne, now remembering who he truly is, tries to uncover hidden truths about his past



**Absolutely Fabulous the Movie** Comedy : The film stars Saunders, Joanna Lumley, Julia Sawalha, is directed by Mandie Fletcher, based on the television show The ever glamorous and self-indulgent Patsy & Edina find themselves at the centre of a media firestorm when they accidentally kill Kate Moss.

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[www.craniofacial.com.au](http://www.craniofacial.com.au)

September

**Craniofacial Australia\* & Adelaide Combined Lodges**



**Tickets only \$19 for 2 Movies**

At the Mitcham Cinema  
119 Belair Road Torrens Park

Another Great **Double Movie Night**  
**Sunday 25th September 2016 @ 6pm**





**Bridget Jones's Baby**  
Comedy  
Breaking up with Mark Darcy (Colin Firth) leaves Bridget Jones (Renée Zellweger) over 40 and single again. Feeling that she has everything under control, Jones decides to focus on her career. Suddenly, her love life comes back from the dead when she meets a dashing and handsome American named Jack (Patrick Dempsey)



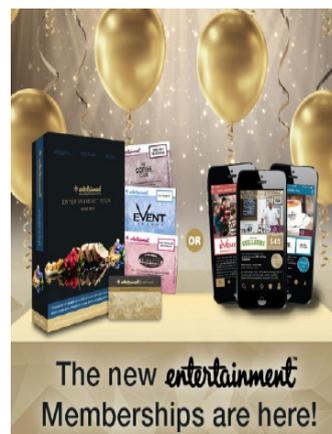
**Sully True Story**: Film stars Tom Hanks & Directed by Clint Eastwood. On Jan. 15, 2009, Capt. Chesley "Sully" Sullenberger (Tom Hanks) must land US Airways Flight 1549 in New York's Hudson River after the plane strikes a flock of geese and gliding his plane along the water in the Hudson River, saving all of his 155 passengers.

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[www.craniofacial.com.au](http://www.craniofacial.com.au)

## 2016/17 ENTERTAINMENT BOOK

The 2016/17 Entertainment Book has arrived. Get your copy before stocks run out. Did you know the books is available as a digital version as well? No more forgetting to take the card with you. Simply download the app and off you go. To arrange your copy contact Chris on 8267 4128 or go online to our website and follow the link..



# 2016 Toyota AFL Grand Final Raffle

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**Tickets now on sale for your chance to win a trip to the  
2016 Toyota AFL Grand Final**

**Call 8267 4128 or email  
raffle@acmff.org.au**

**Tickets are \$30 each**

**Raffle will be drawn on 31st July, 2016  
@ Craniofacial Australia's Office  
226 Melbourne Street North Adelaide SA 5006**

**AFL Authorisation Code GFAFL16/65  
see our website [www.craniofacial.com.au](http://www.craniofacial.com.au) for full terms & conditions**

## EVENTS DIARY

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Bequest Breakfast

AFL Grandfinal Breakfast & Game Day

Cocktail Reception

Breakfast with the Stars

Harry's Welcome Back Dinner

Children's Xmas Pageant Day Picnic

New Year's Eve Dinner

Smile Ride - Bupa Challenge Santos TDU

A Valentine Affair

Register your interest on our website

@ [www.craniofacial.com.au](http://www.craniofacial.com.au)



# Update on our overseas Outreach Programs

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Professor David with Indonesian colleagues at InaPRAS 2016, Makassar Indonesia

April saw the beginning of new things to come, with a trial of our very first Webinar. Families from an Australian Craniosynostosis support group website were invited to logon remotely and listen to a live presentation by Professor David. Following the presentation, a question and answer forum was held allowing participants to speak directly with Professor David on questions relating to the material presented.

Another successful overseas clinical visit was conducted by Professor David in May, with him visiting Singapore, Jakarta and Makassar. Many new and old patients were seen as well as many lectures delivered. While in Jakarta he was invited by Professor Benny Latief to conduct a lecture to Medical Students and nursing staff at the OMFS Universitas on ‘Crani-ofacial Surgery in General’.

In Makassar he was invited to lecture and attended the “The 20th Annual Scientific Meeting of Indonesian Association of Plastic Reconstructive and Aesthetic Surgeons (InaP-RAS).” His presentations included “Esthetic Face Contouring” and “Removing the Stigma of the Cleft”. The forum allowed the opportunity to come together with fellow Indonesian Colleagues to compare, discuss and learn all things to do with Craniomaxillofacial and more.



Professor David with Dr Asmarajaya from Bali Indonesia and Dr Sidik Setiamihardja from Malaysia

# Thank you to our Sponsors

## Platinum Sponsor



## Sponsors



## Supporters



SCARPANTONI  
PREMIUM WINES OF MCLAREN VALLEY

If you would like to make a donation, please complete the slip below & return to our office. Thank you!

Surname  Given name  Business Name

Street address

Town/Suburb  P/code

Phone (optional)  Email

Cheques should be made payable to 'ACMFF'. All donations over \$2 are tax-deductible

Pay by: Cheque  Mastercard  Visa  Amex  Diners  \$

Cardholder name

Card number

Expiry date  Signed:

We value your right to privacy.  
We will never release your  
personal data to any third party  
without express permission.



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changing the face of the future

226 Melbourne Street  
(PO Box 1130) North Adelaide SA 5006  
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Registered charity No. CCP653

A registered charity (CCP653) supporting the Australian Craniofacial Unit through patient care, family support, education, training & research

