



# HeartKids of SA

## Newsletter

### Winter 2007

Volume 2007 Issue 3

Winter2007

## The National Conference Report

On the weekend of the 13 – 15 July 2007, Heart Kids of SA hosted the fourth National Conference and the 2<sup>nd</sup> get together as *HeartKids Australia*<sup>TM</sup>.

The *HeartKids Australia* AGM on the Friday evening was held at the Old Adelaide Inn, and the two South Australian representatives Matt Turner and Lee Morgan were nominated and accepted onto the National Board.

On the Saturday 14 July, delegates convened at the board room in the Samuel Way Building at the Women's and Children's Hospital. The morning worked through some simmering state differences and a

collective refinement of HeartKids Australia's Vision of "*Embracing the future for HeartKids*" and a National Heartkids Australia Mission statement. This was ably facilitated by business mentor Steve Shepherd from Shirlaws Limited Sydney, who provided his time pro bono.

The Mission of HeartKids is now as follows:

***"Australia will have a reduced incidence of children with heart disease, a reduced mortality rate in children affected by heart disease and significant support will be provided to HeartKids families. This will be achieved through the development of: Research, Support, Awareness, and Advocacy".***

At about 1pm we had a flurry of activity as the morning session was wound up, then media interviews for the Channel 7 news (If you did not see it, you can view it on our website - [www.heartkidssa.org.au](http://www.heartkidssa.org.au)), and the arrangements for the afternoon forum in the WCH Theatre. Interstate delegates were joined by a good number of HKSA committee and general members for this information forum.

Indeed they were not disappointed with a presentation by Dr Gavin Wheaton who talked about our "*single most common congenital abnormality*", and the surgical mortality of TGA, fallots, coactation of the Aorta, ASD, VSD and PDA.

Dr Wheaton highlighted the large coverage of our WCH Cardiology team to outreach clinics from Mt Gambier in the south to Darwin in the Northern Territory.

Our second speaker was Dr Patrick Disney who talked about the transition from paediatric to adult care, particularly as there are a limited number of cardiologists trained in Adult Congenital Heart Disease (ACHD), especially as there is a rapidly enlarging population of young adults with congenital heart disease and the need to provide an adolescent transition clinic.



Dr Gavin Wheaton at HKA FORUM



From left : HKSA Chair & Vice Chair HKA Board - Lee Morgan, Facilitator - Stephen Shepherd, CEO HKA - Neil Mc Whannel, and HKA Board Chairman - Dr Dom Frawley

## National Conference continued ... ..

Our third speaker was Dr Dorothy Scott who provided an inspirational presentation about the importance of children to thrive and the important role we have as parents. This presentation was just pictures, and yet as one delegate who said after (who has seen up to 500 PowerPoint presentations) he remarked it was the best one he had seen. Our final speaker was Heather Ashmeade who provided an informative presentation on the Department of Education and Children's Services – on Child Health and Education Services about receiving health support including health care plans medication, equipment, and curriculum in the school system. Further information can be obtained at [www.chess.sa.edu.au](http://www.chess.sa.edu.au). The forum concluded with an inspiring speech by our National CEO Neil McWhannell.

The forum provided an excellent opportunity to expand the delegate's thinking as an organisation on matters such regional outreach, transition from children to adults and helping our children to thrive. Indeed it was a honour for SA to be the first state to be inclusive by allowing its members to be involved by holding the forum.

After this afternoon forum, the executive managers met with the National CEO Neil McWhannell, whilst the Board worked through its strategic planning with Steve Shepherd, concluding well after 6.30pm. At 7.30 over 40 people had a lovely dinner at the *Basil and Lemon Grass* in O'Connell St (highly recommended).

At 8.00 am on the Sunday, the Board reconvened at the Old Adelaide Inn for a Board Meeting and was joined by the Executive Managers and Parent Support Coordinators to develop priorities for HKA staff and our CEO. It was pleasing to note that all delegates were unanimous in providing support for an employee(s) for South Australia, and Matt Turner and Lee Morgan will be providing a submission to the board at its September meeting. In summary, the outcomes of the national conference for South Australia could not have been better for Heart Kids of SA, and this was primarily through the incredible mentoring by Stephen Shepherd. The success of this conference put *HeartKids Australia*™ in good stead as ultimately the best children's charity.

Well done to all of those who attended the proceedings and especially those who helped with the organisation of this major event for 2007.



After a photo shoot near the pool, it was time for the thank you's and acknowledgement that South Australia had done a great job in organizing the conference, and then it was time to wind down through the courtesy of the Kiwanis Bus (thank you Adelaide Hills Kiwanis – Ashleigh Gore) to a sandwich lunch at the bay generously provided by the Glenelg Kiwanis, thankyou Bruce Wright and fellow Glenelg Kiwanis. Then delegates were driven to the Airport by Ashleigh on the Kiwanis Bus.

*Most of the conference participants including heather Hudswell, Matt Turner, Rowena Whewell, Cathie Turner, Lee Morgan*

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Serving the  
Children  
of the World

Supporting HeartKids of SA

## The Conference Photo Album ...



The Board : from left Clare Fountain , Dianne Lunt, Dom Frawley (Chair) , Darren Pratt, Matt Turner, Lindy Toon, Ryan Payne, Lee Morgan (Vice Chair).



Executive managers : Fran Maunton (WA), Neil McWhannell(CEO), Janet Pratt (Qld) Alson Byrne (Vic), Kathryn Meekings (NSW), Kerri Robertson (Qld) Dawn Everingham (NSW) with Rowena Whewell and Cathie Turner



Family Support Coordinators with Heather Hudswell and our counsellor Jeanette Hall



*"Hear ye Hear ye Hear ye ..."*



## HeartKids SA Annual General Meeting

When is it ? : Tuesday 25 September

What time is it ? : 7.30pm



Where is it ? : Women's & Children's Hospital Meeting Room  
(adjacent Rose Ward , Level 2 Good Friday Building.)



**♥ Thankyou ♥ Thankyou ♥ Thankyou ♥**

*HeartKids SA would like to acknowledge the continued generous sponsorship from James and John Sexton of RE/MAX Hills & Country*

*Getting our newsletter printed in colour and mailed to you quite simply isn't something we could have done without the generous support of James, Julie and John Sexton of RE/MAX Hills & Country.*

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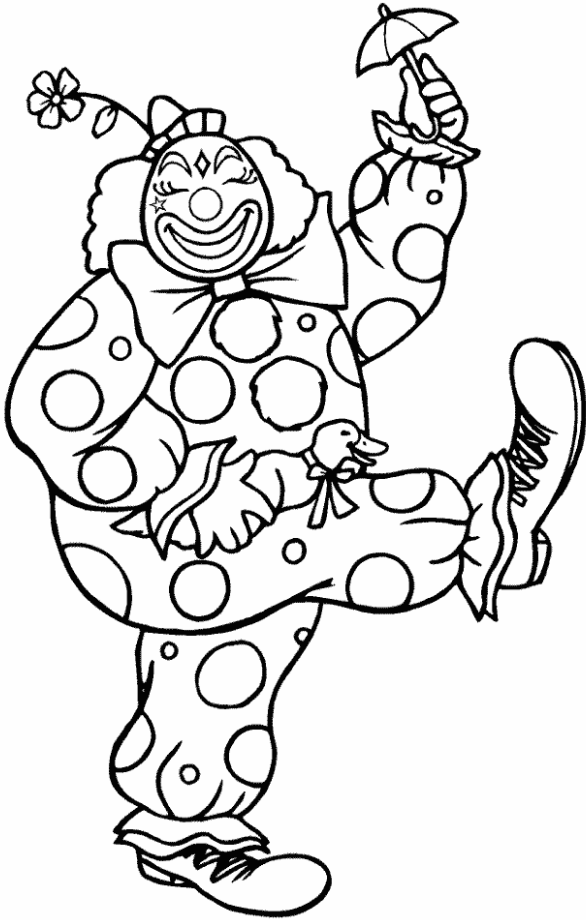
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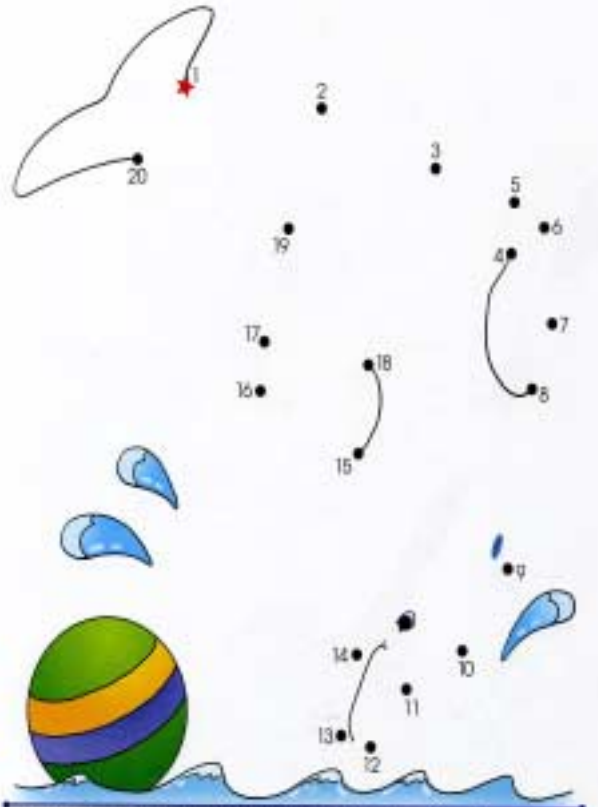
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# ♥ HeartKids Fun Page ♥



Who jumps in with a flip of his fin? 



Connect the dots from 1 to 20. Start at the star ★. Then colour the rest of the picture.

Help Ralphie find his bone.



Draw a line that shows how he must go.

# Who's been fundraising? ...

Interested in Fundraising ??  
Simply contact HKSA and we'll get you started.  
Mob. 0406 165 111.



HeartKids SA wish to acknowledge the many sponsors who so willingly supported the Quiz night back in May - their generosity help to raise **\$1932.00 !!!!!**



Thomas More College  
Bellis Fruit Bars  
Lollyblooms  
Heather Hudswell  
Campbelltown Centre Meats  
The Good Guys - Jim Drivas  
Sportspower  
Woolworths - Modbury Heights  
PALS Liquor  
Tea Tree Gully Hotel

Channel 7  
Profile Partners  
Mawson Lakes Hotel  
North Adelaide Football Club  
*The following businesses are all from the Golden Grove Area ...*  
Auto Pro  
Angus and Robertson  
Price Attack

Home Hardware  
Gauci Hair and Beauty  
Blockbuster Video  
Noodle Box  
Garden Grove  
Ultra Tune  
Village Bowl  
Subway  
B-Select (Bridgestone Tyres)  
State Swim

Thanks again to David & Jodie O'Hare, friends of Matt & Cathy Turner for their initiative to hold the Quiz Night for HKSA.

See the Autumn edition of our newsletter for the full write-up on the Quiz night !



## Gawler Kiwanis Quiz Night



Gawler Kiwanis kindly organised a Quiz Night at the Elderly Centre on 26<sup>th</sup> May 2007. We all had lots of fun! I gave a short introduction on HeartKids and our experience of having a heart kid James aged 15. The room was full of HeartKid posters and information. The Quiz was challenging, but embarrassingly our table pipped the leaders at the post and won dinner tickets in Adelaide. Thanks to Bruce Townsend, President and Ray Hobart the secretary and to Joan the entertainment organiser for fund raising for HeartKids Australia and highlighting our support group to the public. I believe they raised over \$400.  
Janette Hall - HeartKid Parent

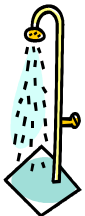


## Gawler Kiwanis HeartKids Picnic (Gawler and Northern Area)

The Gawler Kiwanis are organising a picnic on Sunday 16<sup>th</sup> September at a local Park, time and arrangements to be notified nearer the date. Please come and support HeartKids and get to know other heart kids and their families in our area. Contact Janette if you are interested on 0409 809 504.



## Remember the HOT WATER service donated to HKSA by Bosch ??



To briefly refresh you memory, last year Mix FM102.3 ran a "favourite charity" promotion. HeartKids SA was chosen as the favourite charity, and as a result we were the recipient of a Hot Water Service valued at \$1200 !  
Well yep, we did list it for auction on eBay and a very proud successful bidder from Queensland is now its rightful owner ! HeartKids SA received a net profit of \$1,118.22 from the auction. Congratulations to Tim on a fantastic Ebay listing ... Well done Tim, you did a great job.



Invented for life



Partnering with HeartKids to Make Life Better

St Jude Medical have been the leaders in Mechanical Heart valves for the past 30 years, and have built on that leadership with 20 years experience in Biocor stented tissue valves. To commemorate their 30 year heritage in heart valves, St Jude Medical will be donating \$50 to HeartKids Australia for every St Jude Medical Heart Valve implanted in Australian hospitals during July, August & September 2007. In Recent years, St Jude Medical has donated \$100,000 to the Royal Children's Hospital in Melbourne to support the establishment of a specialised Gene Typing Laboratory – for investigating rare genetic disorders that predispose kids to sudden cardiac death. St Jude is proud to continue its support of medical research for children with heart conditions by making a donation to HeartKids.



Celebrating 30 years of Valve Leadership ... 1977 - 2007

## The Chairpersons Report !



# Lee's last hoorah ... ..

## *HeartKids : Support- Awareness- Research and Advocacy - this is what heart Kids is about.*

Well after five years this is my last contribution as Chairperson of HeartKids of SA. It has been a wonderful journey since the 2002 AGM, where HKSA were battling to fill the office bearer positions and now we have a robust committee that are displaying potential to continue the journey and leadership within the *HeartKids movement*.

During my time I have focused on the following objectives:

- To build capacity of the organisation (both at committee and at the national level)
- To attract members to our organisation (removal of fees, Xmas parties and social functions)
- To respect that HK members are volunteers (vulnerable family circumstances -especially child's health may mean that others may need to pitch in times of need)
- The importance of early childhood development and parenting (always remember that we are parents first and foremost)
- To build up links with the Women's and Children's Hospital (Dr Gavin Wheaton has been a wonderful supporter of HeartKids and we thank him especially for that support).

I will leave you to contemplate how successful HKSA has been over these 5 years, but what I mean by the *HeartKids movement* is that we are no longer just a small committee that organizes an annual Xmas function. HeartKids is now a national network of support coordinators, managers in each state (especially support we receive when families go to Melbourne) and a CEO Mr. Neil McWhannell, in NSW. Jeanette Hall is currently our SA counselor, we have website coordination with Colin Mills, a playgroup being run by Cathie Turner, and a Committee that contributes in many wonderful and diverse ways.

One of the outcomes of the National Conference (in Adelaide July 13-15<sup>th</sup>) was that the National Organisation, which I have been part of since day 1 in Melbourne in 2003, made the unanimous agreement by delegates that seed funding would be provided for a parent support coordinator/ executive manager position here in South Australia. Finally we will have a person that can dedicate work hours to helping build a good family support network as in the other states.

I must pay tribute to the assistance that Deb Signorelli has provided over the last five years in responding to lots of correspondence, organizing tickets and mail outs for newsletters, picnics, charity functions and so on. Along with Deb, Heather Hudswell, Sue Virgili, and my wife Rowena (who has been part of HKSA & committee since 1991), these lovely people have been with me since 2002. I am forever grateful for their continued loyalty, their valuable time and support. I also thank those who have been on committee during that time including Colin Mills, Nicole Dall, Tania Allen, Margot Mallard, Michael Bails, Matt and Cathie Turner, Tim O'Neil, Ed Pikusa, David Oldman, Jo Oldman and Belinda Fullston.

Finally, I am happy to say that I will not be leaving HeartKids completely and I am happy to guide (pending work circumstances) with the transition of the new Chairperson and other new office bearers. I will also not be far away as there is much to be done at the national level in my position as vice Chairperson of HeartKids Australia Board.

Always remember that we are vulnerable volunteers and that being a parent is a #1 Priority. Take care.



Lee Morgan  
Chairperson HKSA Inc. 2002-2007  
Vice Chairperson HeartKids Australia

*Thankyou Lee*

*... from the committee, from the parents,  
from the children ...*

*we extend our gratitude for your  
tireless commitment, dedication, advocacy,  
support, friendship & leadership.*

*From the heart xxx*



## In Hospital

Cathie & Matt Turner have Little Jack in the RCH again. This is their 4th Visit to RCH and they are all in our thoughts and prayers. Cathie and Matt joined the HeartKids SA committee last year and have worked tirelessly for HeartKids of SA and helped organise the HKA Conference recently held in Adelaide. They attended each day being fully involved for the whole conference Cathie organised all the merchandise we now have for sale, and Matt has accepted a position on to The HKA Board, representing all HKSA members. It is one of the issues that came up at the conference was reaching out to help others whilst also sometimes having real emergencies with our own HeartKids, after all we all have HeartKids that is why we belong to this wonderful organisation, and Cathie & Matt have really got behind HeartKids because they can see how the support, advocacy research and awareness can only help HeartKids like their little son Jack.

We wish Jack all the best and that he, along with his mum & dad are reunited with sister Lara again very soon.



get well soon  
little Jack ! xxx

## Entertainment Guide

... support those who support us.



### The Adelaide Gang Show presents "The Weekender"

(a collection of variety acts, songs, dance routines & comedy sketches)

The Adelaide Gang Show represents the Youth Theatre section of Scouts & Guides Australia with the cast members ages ranging from 9 to 27 yrs. They have chosen to use their show as a fundraiser for HeartKids SA and are offering discounted tickets to HeartKids SA members. Last year the Adelaide Gang Show raised funds for HeartKids SA in the same manner and were quite successful, so here's how it works ... for every ticket sold to HeartKids SA members, \$5 will be donated to HeartKids SA. In addition to this, extra funds will be raised through collection tins during the course of their performances. The performance dates for "The Weekender" are from Tuesday 18th to Saturday 22nd September. **Unlimited tickets** are being offered to **HeartKids SA members** at the **discounted price on Monday 17th September** (preview night). If you can't make the 17th, HeartKids SA will still receive \$5 from each HeartKids ticket sale for all other performances, however full ticket price will apply.

**Where :** The Scott Theatre, Kintore Avenue, Adelaide

**When :** Monday 17th September - HeartKids night (preview night)  
(limited tickets available 18th - 22nd if you can't make 17th)

**Time :** 7.30pm each night or 2.00pm matinee show - saturday only

**Cost :** HeartKids night price \$10, Full ticket price \$16 (18th to 22nd)

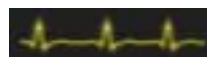
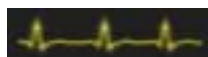
**Ticket Sales :** 8276 6974 (Visa / Master Card accepted) ... .. **please mention HeartKids fundraiser !**



Sacred Heart College  
presents  
"Beats for Beats"



Sacred Heart College will present "Beats for Beats" on Friday 19th October, raising money for HeartKids. The concert features a selection of live music performed by a variety of talented musicians and will be a fantastic evening suitable for all ages. Recent performances at the Fringe Festival proved very popular. As the "Beats for Beats" concert falls between newsletter publications and ticketing information is yet to be finalised, please call Deb on 8374 3345 closer to the date regarding ticket sales.



## Heart Kids Play Group

The brand new HeartKids Playgroup has begun and is gradually building momentum. It's a fantastic opportunity for our heart children to come together and build friendships with other kids who have been through similar experiences. The same can be said for the parents too! We have all had many and varied stories to tell and support to offer but of course we also enjoy NOT talking about heart problems too and instead relaxing with a cuppa, comfortable in the knowledge that our children are playing together in a safe environment.

My 19 month old son Jack has a pacemaker and I am personally enjoying this playgroup because it gives him a chance to play in a great room full of toys and equipment, in one contained area. I feel much more at ease than at a Play-Café or larger playgroup. Another mum, who's daughter is tube fed, feels glad she can be part of a group where she doesn't have to explain it to everybody else in the room! Other parents have commented on the fact that their children get to socialise and play without compromising their general health as we all know how important it is to keep colds and gastro bugs away from our heart kids.

*We are now meeting EVERY THURSDAY morning. We look forward to meeting new families as the year progresses so come along for a play and a chat.*

Cathie Turner (Heart Kid Mum)



Rhylee



Brodie and Roman



Mason

**Forward notice:** On August 30th (week 6) the HeartKids Playgroup will be meeting at an alternative venue, to be advised. If you intend to come along for the first time on those dates please call Cathie for further details. Ph. 0407 070 656

## HeartKids Playgroup

For children with congenital or acquired heart disorders

... in the playroom at Playgroup SA, 91 Prospect Road, Prospect

*Every Thursday morning during school terms.*

10am - 12pm

Siblings welcome too!

For more information please call

Cathie 8263 3626 or Rachel 8556 3111



Need to Contact Heart Kids SA ? ... .. Call the Purple Phone : 0406 165 111



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