



HeartKids of SA Newsletter Autumn 2007

Volume 2007 Issue 2

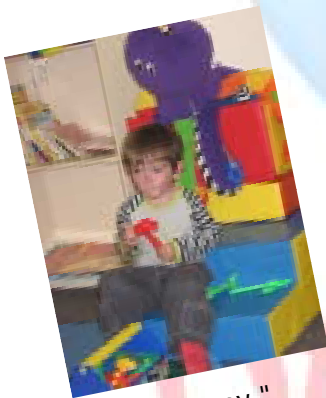
Autumn 2007

♥ HeartKids Playgroup ♥

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 look forward to meeting new families this term so come along for a play and a chat.



" Romy "



" Grace & Jack "



" Jack "

See more details for Playgroup Times on page 5



Serving the
Children
of the World

Supporting HeartKids of SA

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National Conference comes to SA

The Chairpersons Report !



On the weekend of 13 to 14 July 2007, **HeartKids Australia** is conducting its annual conference in Adelaide. The conference will involve Board members, Executive Managers from each state and support workers from around Australia to meet and discuss strategic and operational management issues for our fledgling organisation.

Whilst our journey as *HeartKids of SA* started nearly 21 years ago, **HeartKids Australia** is beginning to offer a national approach towards support, encouragement and hope to families and children with Heart Disease, and collaborating with the medical and research sector, to overcome causes and related treatment barriers of this disease.

For many families, the future of our children is clouded with uncertainty and it is our goal to secure the futures of our very special kids. As we strive to inspire life and bring hope to our kids, we also learn an immense amount from them as they show enormous strength, courage and tenacity on a day to day basis well beyond their years.

At this year's 2007 conference, we have decided to provide an afternoon forum to provoke thinking and to develop positive directions for our children. Parents are intuitive and know that parenting is important. Parenting is not just a guilt trip to keep the Children and teens occupied, as they need time to dream and aspire to develop a sense of self worth.

We as parents may not do it completely right, but by providing that we are warm, consistent, and nurturing, it is that intent in which our kids will ultimately respect you.

Our inaugural national forum has the theme "**The Nurturing of our Heart Children and Teens**" and our professional speakers will present on this theme in their field of expertise. It will also be a chance to meet our new HeartKids Australia CEO and along with the guest speakers there will be a panel based question time, with the forum concluding at 4.00pm.

The forum commences at 1.30 pm on the **14 July 2007 at the Women's and Children's Hospital Theatre**. The forum is open to the general public and HeartKids Australia members, their families and people involved in the charitable and disability sector are encouraged to attend. The forum will be free to HKSA members and a gold coin donation for others.

The forum will provide an excellent opportunity to meet others from across Australia, in what is a very exciting time in our early days as a national charitable organisation.

See you at the **Women's and Children's Hospital Theatre** on the **14 January commencing at about 1.20pm.**

Take care and give your child a hug.

Lee Morgan

Chairperson Heart Kids of SA inc.

Vice Chairperson HeartKids Australia

Kiwani's International
Kiwani's of SA Inc.



HeartKids & Kiwani's go to Air on Radio 5 RPH !

The Kiwani's have been of invaluable support to HKSA. Lee Morgan, Chairperson for HKSA recently recorded a half hour interview on the Kiwani's with John Lundy of 5 RPH. The program will go to air on Friday July 6th at 9.30am & possibly 7.00pm also. Tune in to 5 RPH and hear what Lee had to say.

The Kiwani's ... proudly supporting HeartKids SA



Need to Contact Heart Kids SA ? Contact Cathie on the Purple Phone : 0406 165 111



... the Conference Agenda



"The Nurturing of our Heart Children & Teens" Women's and Children's Hospital Theatre

14 July 2007

1.30pm - 1.40pm	INTRODUCTION BY Dr Dom Frawley 2006-7 HKA Chair HeartKids Australia
1.45pm	"Cardiology Services in SA" Dr. Gavin Wheaton Head of Medicine Women's and Children's Hospital
2.00pm	"Transition from child to adult with CHD" Dr Patrick Disney Cardiologist RAH and Adelaide Cardiology
2.15pm	"The Importance of early Childhood" Professor Dorothy Scott University of SA
2.30pm	BREAK- Afternoon tea
2.50pm	"Child Health Education Support Services-CHESS" Deb Kay, Department of Education and Children's Services (DECS)
3.10pm	"HeartKids Australia – Setting New Directions" <i>To be advised</i> , The new CEO HeartKids Australia
3.40pm	Panel Discussion
4.00pm	CLOSE

*** NEW NEW NEW ***

HeartKids SA has started a new way for members to communicate and share their stories.

It is an internet 'group' where HeartKids of SA members can post their stories and ideas,
and share them with others.

We hope it will create a place where families of HeartKids can get to know each other better.

To use the group, you just need to do 3 things:

1. Log on to the Heart Kids SA Discussion group at:

<http://groups.google.com/group/heart-kids-south-australia>

2. Register a 'user' of the Google Groups. It's free!
3. Read what is there, reply with your own stories and opinions, or start a new conversation of your own.

Please note that entry to the group includes an 'adult content' warning, as it has been assumed that people may want to discuss hospital experiences.

We look forward to hearing from you, and hope that SA families of HeartKids will help it become a useful resource.

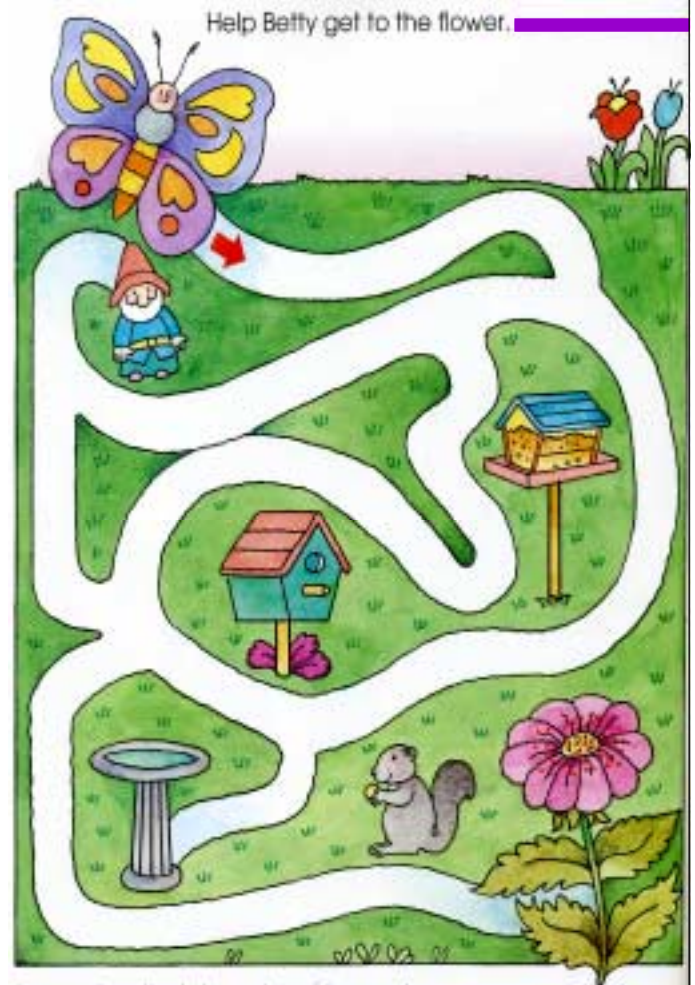
Contact Ed Pikusa for more details - Home: 8556 3111, mob: 0434 660 620, email: ed-rach@bigpond.com



♥ HeartKids Fun Page ♥



Colour in Winnie the Pooh & Piglet to brighten their day



Help Betty get to the flower.

Draw a line that shows how she must go.

Cardiology Word Find! . . . see if you can find Dr Wheaton's & Dr Robertson's favourite words

J N Q W X Q Z U V Z F W J W U L D I F O
 I T A J M U I R T A E G Z S Y Q R O S R
 B O C P J G I W R H E N Y C M R D U E L
 L Q Y B R W M Q Y E E I I W M J E P A C
 U T E V L A V K E R K A Z E K Z P T L K
 E E N E R Z O I Z U B A R B V I Y I R A
 E L C I R T N E V V L C M T Z K N C I A
 L E J W J P L Y O C O J S E A I R X T H
 F D R R O B E R T S O N R T C N P B V E
 Z X X S U T R A E H D E G N R A G Q K A
 O N O T A E H W R D D Z W U U H P E Z R
 X N R E G O C D Q G Z R T H Z Q M P L T
 I N M A O R T A S V L O X S C D I D Z K
 O Z N E G Y X O P U E X A O M W H X F I
 Q S S B E C H O C A R D I O G R A P H D

HEART
 VENTRICLE
 ATRIUM
 VALVE
 ARTERY
 VEIN
 AORTA
 CLINIC
 DRWHEATON
 DRROBERTSON
 ECHOCARDIOGRAPH
 BLOOD
 RED
 BLUE
 OXYGEN

PACEMAKER
 SHUNT
 ZIPPER
 HEARTKID
 HEARTANGEL

Look carefully . . . some words might be Up & Down, Diagonal or even Backwards!



The Choosing of Special Mothers

Most women become mothers by accident, some by choice, a few by social pressures, and a couple by habit. This year, hundreds of women will become mothers of special-children.

Did you ever wonder how mothers of special needs children are chosen?

Somehow I visualise God hovering over the Earth selecting His instruments of propagation with great care and deliberation. As he observes, He instructs His angels to make notes in a giant ledger.

'Armstrong, Beth, son. Patron Saint, Matthew.

'Forest, Marjorie, daughter. Patron Saint, Cecilia.

'Rutledge, Carrie, Twins. Patron Saint... Gerard.

He's quite used to profanity.' Finally he-passes a name to an angel and smiles. 'Give her a special

child.' The angel is curious. 'Why this one, God?

She's so happy.'

'Exactly,' smiles God. 'Could I give a special child to a mother who does not know how to laugh? That would be cruel.'

'But does she have patience?' asks the angel. 'I don't want her to have too much patience, or she will drown in a sea of self-pity and despair. Once shock and resentment wear off, she'll handle it.'

'I watched her today. She has that sense of self and independence that are so rare and so

necessary in a mother. You see, the child I'm going to give her has his own world. She has to make him live in her world and that's not going to be easy.'

'But Lord, I don't think she believes in you.'

God smiles. 'No matter I can fix that. This one is perfect. She has just enough selfish-ness.'

The angel gasps. 'Selfishness? Is that a virtue?'

God nods. 'If she can't separate herself from the child occasionally, she'll never survive.

Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realise it yet, but she is to be envied.'

'She will never take for granted a spoken word. She will never consider a step ordinary. When her child says 'Mummy' for the first time she will be a witness to a miracle and know it. I will permit her to see clearly the things I see - ignorance, cruelty, prejudice and allow her to rise above them. She will never be alone. I will be at her side every minute of the day of her life because she is doing my work as surely as she is by my side.'

'And what about her patron saint?' asks the angel, his pen poised in mid-air.

God smiles. 'A mirror will suffice.'

Erma Bombeck.



HeartKids Playgroup

For children with congenital or acquired heart disorders

Held at Playgroup SA, 91 Prospect Road, Prospect

Every 2nd Thursday during school terms.

School weeks 1, 3, 5, 7, 9.

10am - 12pm

Siblings welcome too!

For more information please call

Cathie 8263 3626 or Rachel 8556 3111



PLAYGROUP SA
Playing, learning, supporting families

The Special Zipper



In August last year, parents of heartkid Connor O'Neill followed the lead of Kyle MacDonald, who traded 'one red paperclip' for a house over 12 trades, by kicking off an Internet up trade challenge. The challenge commenced with 'the special zipper', being a clothes zip representing the scar that many of our heartkids proudly bare on their chests.

The zipper was traded internationally on the first night with the California Heart Connection for a 'heart hugs' teddy bear. This in turn was traded with Alison Byrne, Executive Manager of Heartkids Victoria, for a cap supplied by Stussy and signed by Tim Campbell of

Home and Away fame. The third trade saw the cap exchanged for a gold bracelet which in trade four was swapped for a \$250 gift voucher from the jeweller Karran's of Hyde Park. The fifth trade saw legendary cricketer Dennis Lillee signed a limited edition print from his personal collection which contains eight photos of his bowling action, which was then framed.

Tim and Tarnya O'Neill have pledged the money from the final trade to Heart Kids Australia who are managing an account for the challenge with the specific purpose of assisting South Australian families traveling to Melbourne for heart surgery. Already the account sits at around \$1000 with fundraising occurring in tandem with the trade up challenge. Auctioned to date are a poster signed by the Wiggles and an Adelaide Crows Jumper signed by the 2007 team.

Tim and Tarnya are currently seeking a sixth up trade. The crucial aspect of the challenge is that each trade must result in the traded item being of significantly higher value than the previous item. If you have something you would like to offer as an up trade for the 'Signed Limited Edition Dennis Lillee Print', send an email to Tim and Tarnya at beatinghearts4kids@aapt.net.au or phone Tim on 0438 601 827. Alternatively, you may be aware of a business or company that could assist either with the up trade or just by providing more items that could be auctioned.

The uptrade challenge can be viewed at www.beatinghearts4kids.blogspot.com or by Googling "the special zipper".



Special Zipper Trades So Far

"Glynns story" as he turns 18 & leaves WCH

I will never forget meeting a little boy in RCH Melbourne who was 6 years old and had undergone 6 open heart operations. His mum and Dad were the driving force in starting up heart Kids of South Australia together with a small group of kind heart kid parents who got us through those early years. He died at 22 years of age, but his bravery gave us all hope for our heart kids. So as Heart Kids of South Australia celebrates 20years let us remember all the Heart kids and their families that have touched all of our lives as members of this wonderful organisation.

As I reflect back on the almost 18 years we have been involved in Heart Kids of South Australia, I realize it is this organisation alone that has helped us most to cope with having a child born with Childhood Heart Disease. It has supported us as he survived all the medical traumas. He was airlifted from Adelaide by the Royal Flying Doctor service to Melbourne when he was only 36hours for life saving surgery. Struggling as a very sick baby for the first 2 years of his life, before the Open Heart surgery to construct a pulmonary artery into his heart at Royal Children's Hospital in Melbourne. Heart Kids phone numbers were our lifeline. I knew I could pick up the phone and talk to some one who had been through the same.

At 5 years our son was collapsing into unconsciousness. He had a pacemaker fitted at 6 years of age to correct arrhythmia's . By 16 years of age he had had 16 admissions to hospital, sometimes for up 4 weeks at a time, The waiting as he underwent heart surgery, cardio catheters & stress tests, being told he might drop dead if he played sport. All were hard to deal with alone. He suffered a Ventricular Fibrillation whilst having a baby tooth out at 7 years of age, and was treated twice for suspected endocarditis. He became a 'pin cushion' from all the blood tests, and suffered post traumatic stress as a result. Now he is a teenager, Heart Kids has proved invaluable in helping him come to terms with this life long condition. Being a child that has undergone so much hospital intervention, I have realized that the hospitals only try to fix his heart problems. No one helps with the trauma the child and family suffers. It is only by the support of other families can we share and feel supported by those who really understand.

As he goes back for more surgery in early Feb. 2007, I know he really values the support of the young friends he has made in HeartKids, and they give him courage to keep facing the challenges he needs to face to live.

His parents - Rowena Whewell
Lee Morgan - Chairperson, Heart Kids Of SA Inc.

Hospital transition for HeartKids as they reach 18.

I remember all those times in Glynn's life when I thought he would never make it. but on October 19th 1988. we celebrated his 18th birthday. He was in the last throws of study and preparing for his year 12 exams, so it was a family dinner that night, with the party for 40 odd school friends to be held in December after the exams.

With all the excitement of finishing his last term of school, Glynn also had to deal with the frustrations of heart rhythm problems, related to his 12 year old pacemaker. He was suffering episodes of sudden heart rate drop, which made him feel very faint. It was decided to help him get through his year 12, the pacemaker rate would be turned up. In the middle of all this Glynn's 18th birthday had brought the realization that if Glynn was to collapse at school he could not be admitted to the Women and Children's Hospital anymore he was now too old.

As he did not know any Cardiologists anywhere else, it was decided by us (his parents) that Glynn needed to see Dr Patrick Disney sooner rather than the next due appointment for his regular 6 month checkup. Dr Patrick Disney is the Cardiologist that runs the transition for our HeartKids leaving the Women & Childrens Hospital. With all things in life HeartKids have move to the next stage. Letting go of their parents doing all the caring and taking on the responsibility for themselves as young Adults with Childhood Heart Disease (ACHD).

The first appointment is made to see Dr Disney in the Cardiology Dept of the Women and Children's Hospital. Its much the same, the environment is familiar, just the Dr is different. Glynn was very impressed, as were we, with Dr Disney's ability to listen to Glynn and talk directly to him. At this visit he is able to access all Glynn's files and makes note for himself to set up a file at the RAH or Wakefield Private Hospital.

ACHD patients can continue seeing Dr Disney at the Cardiology Dept, for their checkups, or Wakefield St or The Royal Adelaide Hospital.

Glynn felt that the RAH would be a good transition for him. He wanted to feel grown up.

Due to his Heart rhythm problems it was decided to have Glynn's pacemaker changed at Wakefield St as he needed it doing in the new year, before Uni started and he could get it done there.

Dr Young from Adelaide Cardiology performed this procedure at Wakefield St Hospital.

So Glynn now sees Dr Glen Young for pacemaker checkups at Adelaide Cardiology, in Wakefield St. and Dr Disney at the RAH ACHD clinic, 6th floor Outpatients building (even the same level six)

We will always remember the Wonderful care Glynn got by the fabulous staff at the Women and Children's Hospital

He had his first visit to the RAH on Tuesday to see Dr Disney and he said it felt good. He liked the way he was spoken to, and said it didn't feel too far removed from the Women and Children's Hospital.

So this transition from The Women and Children's Hospital although scary, has worked very well for Glynn he feels he is still in good hands and gets on very well with his 2 new Specialists.

We hope families with a HeartKid about to approach that magical age of 18, can find some hope from our sons positive experience.

Parents,
Rowena Whewell
Lee Morgan - Chairperson, Heart Kids Of SA Inc.



Teen Camp 2008



*Do you like to ... get out of the house ? ... get little sleep ? ... have fun ?
... be adventurous ? ... make new friends ?*

Then TEEN CAMP is for you !!! So watch this space in the next newsletter edition for all the details.

*Grab a copy of our last newsletter and read the wrap from last years camp ...
... you won't want to miss the fun !!*

TEEN CAMP coming to you again in 2008 !

Who's been fundraising? ...

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

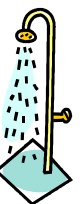
Three Cheers for the Kennedy Family !!



... .. Elaine (Mum), Alan (Dad), Phillip (HK & veteran of 3 Teen Camps) & Neil (brother) donned the aprons, grabbed the tongs & fired up the burners at Woolworths in Gawler on Sunday 4th March. They just kept "chuckin another snag on the barby" and when the coffers were counted, \$240 came HeartKids way. Well done folks, a real "sizzling" effort !!



Ever thought getting into HOT WATER would pay dividends ??



Well through heartfelt generosity, Bosch have donated a Hot Water Service ! Last year Mix FM102.3 ran a "favourite charity" promotion, with listeners phoning in to recommend their favourite charity. HeartKids SA was chosen as the favourite charity, and with thanks to State Manager of Bosch Hot Water Systems, Mr Kent Retallack, we were the recipient of a Hot Water Service valued at \$1200 ! We will auction it on eBay during the winter, so stay posted for the listing date and keep a watch full eye on eBay.



A big HeartKids "THANKYOU" to Bosch Hot Water Systems & Mix FM102.3

Invented for life



BOSCH

Quiz Night tables \$1932.00 for HeartKids SA !!!!!



A few months ago we were very lucky to have some friends of ours, David and Jodie O'Hara, approach us with an offer to hold a Quiz Night to raise funds for Heart Kids of SA. The Quiz Night was held on Saturday 19th May at Thomas More College, Salisbury. When we first began planning the night we had space for 96 people. I wondered how we would find that many people to attend but as it turned out it only took one friend or family member to organise seven of their friends and a whole table was taken care of! We had it booked out fully within two weeks and had to turn at least 5 tables down!

Dave organised the rounds of questions while, with HKSA's permission, I visited local businesses asking for donations that we could use on the night for raffles and prizes. Many businesses were very generous and we ended up with lots of fantastic prizes, vouchers and giveaways.

Each table brought along their nibbles and drinks to share and of course a bunch of coins to get involved in the games between rounds. We had lots of HKSA posters, balloons and banners decorating the room and my husband, Matt, and I gave a short presentation about CHD, HKSA and our own story of our heart kid, Jack.

Everybody had a great night of fun and we raised a fantastic total of \$1932. And the other great thing is that a huge amount of people who never really knew the facts about CHD now do and hopefully they will support our worthy cause again in the future and urge others too as well.

Cathie Turner.

If you are interested in holding your own Quiz Night to support HKSA Cathie is more than happy to offer advice and assistance. Just contact HKSA on 0406 165 111.



David O'Hara

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