Our Vision: Life unaffected by Childhood Heart Disease

Our Mission: As the public face of Childhood Heart Disease (CHD) and through our active partnering with the medical community and Government, Australia will adopt best practice in the intervention, treatment and support for all those affected. This will result in a reduction of incidence, decreased mortality, significantly improved quality of life and best outcomes for those affected by CHD.

This will be achieved through our work in support, awareness, advocacy and research.

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Heart Kids WA Office

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Heartkids Western Australia Life Members

Lin Quinliven (1989)
Edna Boyes (1989)
Tanya Tinetti (1993)
Adele Schober (2004)
John Bignell (2009)
Fran Maunton (2011)
Cecilia Donovan (2011)

DISCLAIMER: PLEASE REMEMBER THAT THE OPINIONS EXPRESSED IN ANY ARTICLE HEREIN REPRESENT PERSONAL EXPERIENCE ONLY, MEDICAL DETAILS ARE SPECIFIC TO EACH INDIVIDUAL CASE AND MAY NOT BE APPLICABLE TO ANOTHER CHILD. PARENTS WHO REQUIRE MORE SPECIFIC INFORMATION SHOULD CHECK WITH THEIR CHILD’S OWN DOCTOR. ALSO PLEASE NOTE THAT THE OPINIONS EXPRESSED IN THE ARTICLES HEREIN, ARE THOSE OF THE AUTHOR AND DO NOT NECESSARILY REPRESENT THE BELIEFS OR OPINIONS OF HEARTKIDS WA INC.
### July
- **6th Wednesday**
  - Kalparrin Coffee & Chat
  - Questions & Answers—Guest from Cardiology
- **9th Saturday**
  - Teen Event—Private Movie Screening at Jaffa Room
- **20th Wednesday**
  - Kids Outing—Movie Night Compliments of Ikea
- **27th Wednesday**
  - Bereavement meeting
  - Guest Facilitator—Tamara Cohen

### August
- **6th Saturday**
  - North of River Coffee & Chat
- **25th – 27th**
  - National Conference

### September
- **3rd Saturday**
  - Father’s Day Event—TBA
- **7th Wednesday**
  - Bereavement meeting—Scrapbooking
- **16th Friday**
  - Kalparrin Coffee & Chat Special Guest TBA
- **30th Friday**
  - Teen Event—Hummer Ride & Dinner

### October
- **3rd Monday**
  - Kalparrin Coffee & Chat—Interstate surgery (families whose heartkid has or will be having surgery interstate)
- **21st – 23rd**
  - Family Camp, Point Walter—Bicton
- **28th Friday**
  - Kids Outing – Zoo Sleepover

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**Please make sure you contact the office on 9340 7996 to RSVP for events so you don’t miss out.**

Please note for some outings there are limited numbers and age restrictions to avoid any disappointment please book early.

You can book by phoning 93407996 or 0417 417 203 or email hkwa@heartkids.org.au

HeartKids WA Inc now has its own Facebook page come and “Like” us to share your stories, receive updates on upcoming events, view photographs & feel the love!

HeartKids WA have produced a DVD which featured recently at the Heart of Gold Ball. HeartKids WA “Look at you now”: http://www.youtube.com/watch?v=Fcj8ulWWR1E
Welcome to the winter edition of the HeartKids WA Newsletter!

Well the cold certainly has settled in, but the gorgeous warm winter sun continues to shine, I hope this is helping all our precious HeartKids stay well? This is certainly the weather to be indoors sharing warm cups of soup, hot chocolate, coffee and tea and whilst you are at it you could share it with your family, friends, work colleagues or community and support HeartKids WA by hosting a Cuppa for HeartKids! The Cuppa for HeartKids program is running again in August and September – full details & how to register can be found at www.cuppaforheartkids.org.au. I would like to encourage you to get behind this program and help us raise some vital funds for our Family Support Program.

Our major supporter The Mortgage Gallery held their annual conference in June celebrating 20 fabulous years! We would like to congratulate John Bignell and The Mortgage Gallery Team on such a momentous occasion – the kindness and compassion shown by everyone at the Mortgage Gallery towards HeartKids WA continues to astound me. They not only contribute to us financially but also many of the team contribute personally - volunteering on our Board, committees, in our office and fundraising for us with initiatives like the recent Cycle Challenge. We are a better organisation today because of the support of The Mortgage Gallery – John Bignell & TMG Team we thank you!

The 8th Annual HeartKids National Conference will be held during August in Sydney this year and will coincide with the first ever National Seminar for families affected by Childhood Heart Disease. This initiative has been designed to bring together families to hear from some of the leading practitioners in the field of CHD. Details of the program are available via a link on our website www.heartkidswa.org.au or by calling the office 9340 7996.

The much anticipated Family Camp will be held on the weekend of the 21st – 23rd October this year, we have an exciting new venue booked this year at the Point Walter Recreation Camp, it promises to be a wonderful weekend. The camp provides the opportunity to relax, share experiences with emotional support and strength from other HeartKids families, build friendships and participate in some fantastic activities, I urge you to book your spot early - places are limited!

Are you on FACEBOOK? If so you can help HeartKids WIN a share of $200,000 by simply voting in the Commonwealth Bank Community Seeds program. HeartKids supporter & friend - Ian McMullen has done just that and is influencing others to do the same, currently Ian is the second highest vote influencer, if he wins he will not only make and extra $5k for our charity but will earn $5k for himself which he will put towards a charity bike ride to fundraise even more money for HKWA! There is still over $100,000 to give to charity – so please go on & vote for HeartKids – www.facebook.com/commonwealthbank While you are on Facebook don’t forget to come on board and join our page too at HEARTKIDS WA INC… we would love to see you on there!

Heart hugs,

Belinda Frank
Hello to Everyone,

I have been sitting for some time now, pondering as to what I could possibly write which could be of any interest to our members and readers. And... as I reach into the cupboard to get yet another snicker bar for inspiration - it happens, an idea pops into my head. So you see... chocolate does have its good points.

Heartkids WA has been running for some time now – over 30 years. We are a parent support group and initially we started out with just a parent or two, corresponding with another. Essentially that is still what we are - a parent support group, connecting heartkid families with other heartkid families.

However over time, the awareness of Heartkids WA and Heartkids Australia has grown, and with sponsorship, donations and fundraising we have maintained and developed our services. We still have a long way to go, of course. However throughout the years we have gained some insight into what our members want, need or like.

So whilst most of you may be aware of what we offer, I thought I would mention a small portion of our practical services. This may enlighten you, or it may even spark a thought, or trigger you to make a suggestion for any other services we could improve on, or expand in the future. I say this tentatively, as whilst our aim is to always offer the best possible support to our families; it is sometimes restricted due to time staffing and finances.

If you are in hospital with your child for any reason, we hope to ease your stress and worry and will always endeavour to pay a visit and bring you something to eat or drink should you wish. If you are in for some time we may be able to help with a small emergency fund (conditions do apply). Then there are always the goody bags for your heartkid from Ikea, which are magnificent! And toiletries for the parent, compliments of Heartkids WA. We can however only visit you and give you these if you let us know you are in Princess Margaret Hospital.

We can also help families travelling interstate with emergency funding, again conditions do apply and we can only help if we know of you. Understandably this is a busy stressful time when you find out you have to take your child interstate for surgery, however please remember we may be able to help lessen the burden for you.

For families struggling at home, please, please do not do this on your own. We can’t help if we don’t know what you need. Even if you think it may be out of our guidelines eg equipment etc, please just tell us. If we cannot help, we may be able to point you in the right direction. The same is for any questions or information you may be need, if we don’t know, we will always try to find out for you. Or maybe you just need to talk and share your concerns.

Currently we are very lucky to have Corporate Challenge as one of our guardians. Kane and Alex are absolute angels, and whenever possible, offer our Heartkids, bikes. These are valued around $200. So if you have a heartkid who is turning 5 or older (limit is 10yrs) please let me know should you wish to register for a brand new bike. You do need to be available on the day of presentation to collect the bike.

I have just mentioned a few of our ways we can assist you in your journey; however we offer many more services from our fun and wonderful events, through to our informative coffee and chats.

Heartkids WA are here to share and care for you and your family. Your heartkid and everyone associated with them are the most important people we know. Unfortunately we weren’t given any wonderful powers, so we can’t perform miracles, but we will always do our best to help in any way. Most of all – we are all parents of heartkids and we do understand your worries, sorrows, pain and stress, along with your joy and delight at the little wonders we see through our precious children.

If for any reason I am not contactable via the office please feel free to call my mobile.

Bye for now

Cecilia Donovan

Remember... We all stumble, every one of us. That’s why it’s a comfort to go hand in hand.

Emily Kimbrough
Strategic Plan

Over the past few months the National Board and I have been working on a new 3 year Strategic Plan. This was recently completed and subsequently presented to each State Board by our Chair, Brian E Pereira and our Vice Chair, Dr Anne Fletcher. These meetings were well received and we are fully aligned and that our goals are shared.

The Strategic Plan is an ambitious and exciting one for our organisation, as we work to build on the strong foundations developed in recent years. We look forward to achieving the many goals and to further expanding our scope of work to address the many needs of CHD.

Commonwealth Bank Community Seeds

Readers may be aware that HeartKids was recently selected as one of 6 charities to be part of the Commonwealth Bank Community Seeds program. We have been delighted with the response to this facebook voting campaign, which has seen HeartKids out performing all the other charities.

We therefore stand to receive the lion's share of the available pool of $150,000. It has also been most heartening to see the wider HeartKids family unite as one for this cause. People wishing to vote for HeartKids (each vote corresponding to a $1 donation) are requested to visit:

http://www.facebook.com/commonwealthbank

Childhood Heart Disease Education Seminar

HeartKids is proud to announce its first ever seminar for families affected by Childhood Heart Disease to be held at the Australian Museum, Sydney on Saturday 27th August.

This one day seminar brings together leading medical specialists and allied health practitioners to share the latest and most relevant information for families affected by CHD. In addition to the educational benefits, this also provides a valuable opportunity for individuals, parents and families to share and learn from each other’s experiences.

Topics will include:

• Genes and environment: an investigation into the causes of CHD;
• Effects of early cardiac surgery on the neuro-developmental, emotional and physical development of the child;
• Social and psychological impacts on families;
• The educational experience as a heart child;
• The transition process from paediatric care to an adult care facility;
• Clinical management and lifelong issues associated with adult congenital heart disease.

Registrations have opened and anyone interested in attending can register via www.heartkids.org.au

Neil McWhannell

100% of monies raised go directly to the cause.

Help in the fight against Childhood Heart Disease!

Host a Cuppa for HeartKids throughout August & September

Register at: cuppaforheartkids.org.au
Working with families and delivering excellent care is a major focus of the Cardiology Nursing team at PMH. We constantly reflect on the ways in which we can provide better care for our patients and families. In collaboration with our wonderful play specialist Bernie; Jenny, Kelly and I sat down and talked about what we thought families might want to know before they came into PMH for heart surgery.

We talked about how heart surgery has a major impact on many aspects of life, not only the practicalities of day to day living, but also a considerable emotional strain for families and patients. From our discussion we knew that the pre-operative clinic cannot always address all of these concerns as this clinic can be very busy. We therefore thought that providing a tour of the hospital might help with some practical information for families, which may then decrease stress for families through this hard time.

During this tour we take families around to the Paediatric Intensive Care Unit, Cardiology Department and Cardiology ward. This also provides an opportunity for families to ask any questions. When we started the tours we wanted to know what families thought about the tours, so we asked families to provide feedback via a questionnaire.

We found that families found the experience to be very useful in preparing their child and their family for heart surgery by; reducing fear, getting to know staff, seeing equipment and understanding the time frames associated with heart surgery. Following this feedback, we plan to continue to provide these tours, in the hope that we help our patients and families to the best of our ability.

Thank you

Julie McLean

Social work

Sarah Tucker is the latest member of the Children’s cardiac centre at PMH, covering the social work position, supporting families throughout their PMH experience.

Sarah studied International development and Geography in the UK, spent 4 years working with adolescents and travelling, and eventually settled in Perth in 2001 where she completed her social work training in 2004. Since then Sarah has worked in education, Child protection, and youth counselling both in Perth and the South West.

Sarah has extensive experience working with families and has been part of the PMH Social work department since September 2010 working throughout the hospital but predominantly servicing the infant’s ward 8A. Sarah’s main role is to work in partnership with families providing both practical and emotional support, she is looking forwards to being part of the Cardiology team assisting families through their PMH journey.
What’s been happening

On Sunday 19th June, 100 of our kids got to participate in an amazing workshop with the winners of Australia Got Talent 2010 – Justice Crew! The Justice Crew first did a performance for everyone, before leading a 50 minute workshop – getting everyone up & moving and teaching them some awesome hip hop moves! The kids had a fantastic time and were so inspired by the guys whose vision is to encourage and inspire all people to reach and fulfil their dreams and live life to their fullest potential – the kids certainly were inspired and I am sure many were going home practicing their dance moves!

Special thanks to Justice Crew, Jenny Dyer – Motive Connections & The Mortgage Gallery for making this event possible.

Lawn Bowls Fundraiser

The amazing Meg & Trav Gillard (HK Sharlize) put together another fantastic fundraiser for HKWA last month. With huge thanks to Lake Monger Bowls Club, Terry Cranwick and Richard Gillard - a wonderful day was had by the many teams that entered. But only one team could win, each taking home a $50 voucher for the Kingsley Tavern. Thank so much to our dedicated supporters for helping make a difference -Meg & Trav - they made a fabulous $2500 for HeartKids WA Support services.
29 glamorous ladies stepped out to a beautiful day on Friday 13th. A few of us were treated to a ride in a pink hummer, and a few were treated to a ride in a black hummer. We met for a brief rendezvous in South Perth, before we continued to our destination at the Blue Water Grill in Applecross. There we consumed a sumptuous three course meal, along with plenty of wine and champagne. New friendships were made and old ones reinvigorated. It was such a fabulous day filled with chatter and laughter, a day to be remembered and cherished. I only wish all our friends could have joined us!

Great day had by all...

**South of the River Coffee & Chat**

On Saturday 11th June, 10 HeartKids families got together at Dome in Canning Vale for the South of the River Coffee & Chat. It was a lovely morning out, catching up with each other and a great opportunity for the Dads to come along too!

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**Mother’s Day Outing**

Friends always carry each other in their hearts—whether they live near each other or far apart, friends walk through life together. They’re there for each other no matter what, sharing everything. Friends are connected at the heart…”

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**What’s been happening**
The Mortgage Gallery – 20th Anniversary

The Mortgage Gallery celebrated their 20th Anniversary with their conference held at Burswood in June. As well as their seminars they held the annual Big Race & auction for HeartKids WA on the Saturday, again raising more money for our cause – the total donated to HeartKids over the 7 years of our partnership has now gone to over $350,000.

It was September 2004 when John, Bev & Shelley of The Mortgage Gallery, were introduced to HeartKids; they heard a speech from Alison Byrne about Congenital Heart Disease & HeartKids at the AFL grand final breakfast. It was that day, which would change so many things, not only for John and his family but especially for HeartKids.

Fran Maunton the Executive Officer of HeartKidsWA during those years, recalled how The Mortgage Gallery literally saved our charity, becoming a true partner in every sense of the word. Not only supporting us financially and strategically, but also extending to us a friendship and closeness that we have never experienced before.

This support would continue to grow with the second national heartkids conference held in Perth in August 2005 an event which The Mortgage Gallery would help fund. In 2006 John was appointed Honorary Chairperson for the inaugural HeartKids Australia launch, not only again financially supporting the event but also Chairing our AGM and conference. It was at this time I personally had the pleasure of meeting John & Shelley and even though living in Victoria at that time I knew I would someday have the pleasure of getting to know this amazing family better.

In 2009 John Bignell was honoured with Life Membership of HeartKids WA an award designed to acknowledge outstanding contributions and dedication to HeartKids WA over a period of at least 5 years. It is has been John’s outstanding contributions that have enabled HeartKids WA to embrace positive change, improve service offerings and do the absolute best we can for our member families. It has been Johns passion and commitment to our cause that has in turn been reflected by so many within The Mortgage Gallery Team.

The Mortgage Gallery Team’s support of HeartKids WA is endless, the establishment of the Heart to Heart Ball, todays Big Race, Bowls days, team members serving on our Board & committees, the Cycle Challenge, Office casual dress days to raise funds…just to name a few…they are all always looking for new and innovative ways not only to raise money for us, but help build awareness of our cause in the wider community.

There were more than 980 requests for our services in the last year, The Children’s Cardiac Centre at PMH performed 150 Cardiac surgeries and many more of our children attended PMH for cardiac related illnesses. Through the funds donated by The Mortgage Gallery we were able to meet the needs of these 980 people requesting our support, we made a real difference in their lives. We were able to do this by increasing the hours of our Family Support Coordinator Cecilia Donovan, employing a Regional Support Coordinator Maree Green, we were also able to purchase medical equipment & supplies, provide support packs for our families, run support workshops, provide counselling, send our Teens to National Camp, hold coffee & chat sessions, provide financial support for families in emergency surgical situations, provide meals for families staying on the ward …the list goes on…but the important thing to know is that we could not do any of this without The Mortgage Galleries help.

All of the amazing support that The Mortgage Gallery has been offered to HeartKids WA without ever requesting anything in return. On behalf of everyone at HeartKids WA, everyone whose lives you have helped touch – thank you. Thank you for sharing our vision, our mission, our dreams - thank you for making us a stronger organisation.

I would like to finish by congratulating John and The Mortgage Gallery team on your 20th Anniversary, what an amazing Community minded company you are, we wish you all the very best for the next 20 plus years to come. To say we appreciate you John & The Mortgage Gallery for everything you do for us, is an understatement, you help us make a difference in the lives of all the HeartKids and their families that we support.

Belinda Frank
### 2011 HKWA Merchandise Order Form

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**Address**

**State**

**Postcode**

**Phone**

**Fax**

**Mobile**

**Date**

**PAYMENT DETAILS**

- Cheque or Money Order to be made out to HeartKids WA
- Credit Card
  - Visa
  - Bankcard
  - Mastercard
  - Amex

**Credit Card No**

**Expiry Date**

**Signature**

**CVC (three numbers at the back of the card)**

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Post form & payment to the office:
PO Box 1554, West Perth WA 6872
Our unexpected journey welcoming our second son, Xavier Lucas Horsley, into the world…

I was born with a condition called Transposition of the Greater Arteries. No one knew that my heart was broken before I was born. It came as an incredible shock to my mummy & daddy when I turned a funny shade of blue. The team at SJOG Subiaco and PMH were so caring, friendly & committed in helping fix me & my heart.

I had my first plane ride to Melbourne with the NETTS Medical Flight nearly a week after I was born so that the special Cardiac Surgeons could make the changes to my heart that will make me a big strong boy.

My mummy & daddy tells everybody about the amazing work & kindness that you showed my family & me during my time with you all. I have heard them say they can never thank you enough for helping me fix my broken heart when I was born.

To all the staff at Perth’s Princess Margaret Hospital – Neonatal ICU Ward 6B, The NETTS Team, the Cardiac Ward & Melbourne’s Royal Children Hospital – PICU & Cardiac Ward 7 West

Thank you from the bottom of my mended heart

My family & I will forever be grateful x

Xavier Lucas
(meaning strength)
I am a miracle baby

Resting after the arterial balloon septostomy procedure at PMH the day I was born

6 days old with mum

Xavier aged 5 weeks at home
Hi, I am Mia Evangelellis and I am currently attending Corpus Christi College in Year 9. My favourite subjects are sport, cooking and English. Recently in the school holidays I went to America with my whole family. There were 13 of us consisting of 5 kids and 8 adults. It was really amazing travelling around America and going to Las Vegas, Orlando, Los Angeles, San Diego and MEXICO!!!

Highlights of this trip include Universal Studios in Orlando which had awesome rollercoasters and also the LA Lakers basketball game. At the basketball game we were celebrity watching and managed to spot the Jonas Brothers, Will Ferrell, Eddie Murphy, Gordon Ramsey, David Beckham and many more. It was definitely in the top 10 things I have done.

We also went and saw David Copperfield, went on a cruise to Mexico (My first cruise), went to Disney World, saw all of the celebrities houses, visited the sets of TV shows such as Mike and Molly, Parenthood, Chuck and many others. It is a shame that there were not any tickets left for The Ellen Talkshow or that one of my favourite TV shows - The Big Bang Theory were on holidays. Maybe next time!

The only downside to having a pacemaker when in America is that you can’t go through the metal/security machines so I had to be patted down or go through the new body scanners.

My heart at the moment is going strong and I will not need my next operation to change my pacemaker until I am 21.

Overall America was an amazing experience and my heart is going great. :)

Mia Evangelellis

Joshua Kent Walsh


Joshua’s last ECHO showed that he had moderate thickening of muscle surrounding his valve, & he now has a leaky valve! We go back on Friday for another ECHO, so we’ll know more then!

Joshy is such a happy, cheeky, fun loving little boy- he lives life to the fullest!! He’s very cute & he’s such a pleasure to be around! He loves playing outside with our dog Bella & all his toys. He loves all the shows on ABC2- he dances and sings along to all the songs (It’s so adorable)…

Joshua will soon be celebrating his 3rd Birthday in August! He can’t wait to “have his party with all his friends!”

Skye Walsh
The last time I wrote an article for the newsletter we were bracing ourselves for the Fontan – procedure that was to be Daniel’s next hurdle. It was to be his last surgery of so many. And his doctors were very hopeful all would be going our way this time. So in October 2010, just a couple of weeks into his fourth term of pre-primary, he had the surgery. One of the things I dreaded this time was preparing him for another stay in hospital. Thankfully there had been a few years in-between surgeries, so, being five years old now, Daniel could not recall the last time. He thought it was a great idea to have a sleep-over at the hospital with the doctors making his heart better at the same time… We were happy he took it so well. I had imagined it very differently.

The surgery went well until a blood clot formed that blocked the fenestration Dr. Andrews had just made. The fenestration closed up, blood could not commute between the chambers. Daniel was in trouble. So the operating doctor made another hole near the one that closed up, a smaller one, to ensure there was enough blood flow.

He was in OR for seven hours. It goes without saying my husband and I were anxiously awaiting updates. At first all was good, but when it did not go to plan and hour after hour passed by, the sinking feeling is indescribable.

When we finally did get to see him we got another shock: he was blue. Being a heart kid, of course he had never been a pink boy, but this was the darkest blue I had ever seen on a child! We were told that the surgery was not successful; he would be worse off than he was before. His oxygen saturation was around 60. The Fontan – procedure should have made him better, up to his high 80s was expected. The reason for this was that after the second fenestration was formed, the first one, previously blocked by a blood clot, re-opened. The clot dissolved by itself. So now there was too much blue blood going through the heart and, partly because of the narrowing in his pulmonary artery and partly because of the extra fenestration, not enough blood went to his lungs; not enough blood got oxygenated. Nobody could have predicted this. It was just another one of those unforeseeable things that seem to happen to Daniel. There seems to be a proper way and then there is the Daniel – way.

We were told nothing could be done at the moment. If worse came to worst the last option would have been to take the Fontan down again, reverse the procedure. We would have been back to square one. As parents in a situation like this you go through all sorts of emotions. Guilt, anger, despair; it’s a roller coaster. Daniel was weak, not interested in doing anything, he was angry and did not want me anywhere near him in the beginning. I found this very hard to deal with. He accepted his dad to be close, even the nurses, but not me. He did not take any medication from me for the first week after his operation.

After a week in the hospital we were allowed to go home. Daniel was happy to be back, have all of his family and especially his sister around. But he was just so weak and not at all the boy he used to be. After four weeks he went back to school, for half a day, and at first Daniels teacher even let me stay with him. Seeing his friends made a big difference. He got back to being himself, minus the running of course. And he was still so blue; he looked very different to his classmates. For three months he tried easily, had low SATs and was blue. In January 2011 Dr. Shipton performed a catheter procedure in which he managed to close the bigger one of the fenestrations so that the blood flow through the heart was better. Also since his surgery in October Daniel had been on medication to promote the opening of smaller blood vessels in the lungs; and with better blood flow through to the lungs and better developed blood vessels this procedure was a big success.

The catheter procedure only took two hours, but when we saw Daniel later that day in ICU (where they kept him for observation) he was pink and beautiful! In fact, he was pinker than I had ever seen him. I made people look at his feet; anyone who came near him had to admire his toe nails.

The procedure was a great success. The outcome we had hoped for in October was finally achieved! His SATs were in the low 90s, better than we had dared to hope.

When Daniel came around, he gave me a big smile and said “I can run really fast now!” He must have felt so much better right away. He let us hug him and interacted with us right away. I cannot describe how happy this made us feel! We spent a night in ICU and another one on the ward before we were allowed to go home.

Two weeks later Daniel was able to start Year One. He loves school and everything to do with it. He also joined a soccer club, trains once a week and plays games on Sundays. He loves it and is unstoppable. Each of the three games he plays goes for 15 minutes, and if no extra players are available he can play for the whole time.

In April Daniel was awarded the Lions Children of Courage Award 2011 for facing life’s challenges with exceptional courage. We are very proud of him and very happy for him to be nominated by Heartkids WA for such a wonderful award and an experience he will never forget. He is old enough now to understand a lot of the things he has to go through because of his condition, so being honoured this way meant a lot to him and us.

Iris Prime
Join us for a night of FREE entertainment at the movies! Delicious pizza’s will be served for dinner from 6pm, in the cinema foyer downstairs, then head upstairs at 7pm to collect your drink and popcorn and enjoy the movie.

When: Wednesday the 20th of July Time: 6pm
Where: ACE Cinemas, 500 Hay Street, Subiaco
SEATS ARE LIMITED!

Family Camp 2011
Friday 21st October
to Sunday 23rd October 2011
Where:
Point Walter, 1 Stock Road, Bicton WA

Activities: Something for everyone...
Accommodation: Separate rooms for each Family
How much $100.00 per Family
(HKWA Members)

How to Book:
Registration Form—or via email at:
hkwa@heartkids.org.au or via phone on: 93407996
Book your place now before the 23rd September 2011
Numbers filling quickly...

Great Activities all weekend such as:
Rock climbing/Pony rides/Flying Fox/Massage
and much much more

PAYMENT DETAILS

Cheque or Money Order to be made out to HeartKids WA
Credit Card
Visa
Bankcard
Mastercard
Amex

Credit Card No
___/___/___/___/___/___/___/___/___/___/
Expiry Date
Signature

PLEASE FILL OUT THE REGISTRATION FORM, CUT IT OUT AND RETURN IT TO:
HEART KIDS, P.O Box 1554, West Perth, WA, 6872
Melbourne Cup Lunch
.....The fascination that stops the Nation!

3 Course Gourmet Lunch
with select wines $165 p.p.

Dare to be different!...Join this exclusive event
and help make a difference to the lives of “HeartKids”.

AT - The prestigious ‘Matilda Bay Restaurant’ (upstairs)
Matilda Bay, Hackett Drive, Crawley WA

Tuesday 1st November, 2011
11am to 3pm

Package also includes:
* Champagne on arrival
* LIVE music and dancing
* Screens to watch racing
* Doorprizes for best hat & tie
* Sweeps/silent Auction/auctions

FOR TICKETS CALL: Leonie Allison 0411239472
Email: leonieallison@hotmail.com
Perth Zoo Sleep Over

Friday October 28th
Arrival time 4.15 pm
Ages 8yrs to 15yrs
Call office to register
Cost is $30 per child
Heartkids have first priority
No Adults however limited numbers required to supervise

Help needed PLEASE

Dear Friends and Supporters

This year, HeartKids will again join forces with Ronald McDonald House, Camp Quality and the Starlight Foundation to organize a special Christmas party for the families of our collective charities.

The ‘ALL 4 One Xmas ExtravagANZa’ with presenting partner ANZ will provide children and their families a day of fun, including entertainment, amusement rides and a special visit by the man of the season, Santa.

More than 400 children along with their parents and siblings are expected to attend this special celebration and presents for boys and girls aged 0-16 are very much needed.

To ensure that every child attending receives a present, we would like to ask if you or a business you may know could assist us by donating a new unwrapped gift for Santa’s sack.

If you would like to help, please purchase a gift of your choice and drop it into the Heartkids WA office Level 2 General Services Building at Princess Margaret Hospital on Roberts Road Subiaco. Please phone on 93407996 or Cecilia’s mobile 0417417203 prior to dropping off to ensure the office is attended.

Your donation will be genuinely appreciated and you’ll be on Santa’s good list.

Special thanks from HeartKids WA

Teen Event
Hummer And Dinner Night

Friday September 30th
Dinner Venue TBA
Numbers Limited // Heartkids first priority
6pm arrival at pmh
9.30pm pick up from restaurant
please register your interest at Heartkids office: ph 93407996
Perth Zoo Sleep Over

Coffee & Chat

This is a regular informal get together of Heartkids, parents, relatives and children. The morning is hosted by our Support Coordinator, Cecilia Donovan.

This is an opportunity to share knowledge, hints & tips, stories; and draw strength and encouragement from people in similar situations, over a cup of coffee (or tea) and cake.

Time: 10.00am to 12.00pm
Where: Kalparrin, at Hay St Building, Next to Orthotics & Occupational Therapy PMH.

See page 3 of this newsletter for dates.

Bereavement Meetings

A meeting for Heartkids bereaved parents, family, grandparents is held every few months.

They are informal, coffee mornings that are especially for remembering our children.

Light Lunch Provided.

Please call office on 9340 7996 for details and to RSVP.

See page 3 of this newsletter for dates.

How to become a Member...

Registration is free to join HeartKids. Once you’re registered, HeartKids will be able to provide support, information and a broad range of assistance. HeartKids is a registered charity, established to support children and families who have congenital and acquired heart disease. Our services are free to all registered with HeartKids.

A subscription fee of $25pa is payable if you would like to receive our quarterly ‘Heart to Heart’ newsletter. For further information or to join please contact the HKWA office on 9340 7996 or via email hkwa@heartkids.org.au or alternatively go to our website www.heartkidswa.org.au

Toddler Tints

The funky, educational alternative to current car shades, toddler tints™ are applied to the inside of the window to protect children from the sun. When driving they appear transparent allowing perfect visibility for both driver and child. The toddler tints™ are black on one side with a print on the inside. The self-application required and the size of a single toddler tint sheet ensures that the product is a universal fit. The size of each toddler tint measures 600mm (h) x 800mm (w) and are sold separately.

It’s with great pleasure that toddler tints have forged a relationship with HeartKids WA. Founder Lia Tonich says: “Being a first time mother I understand the rollercoaster of emotions you go through when you have a baby, on top of that should there be complications with your new born you feel so helpless. HeartKids is a fantastic charity helping families who desperately need assistance. $4.95 from every sale toddler tints make through HeartKids will go back to this worthwhile charity.”

To order your toddler tints for $39.95 email Meg Gillard at: megandtrav@optusnet.com.au
For more information check us out at www.toddlertints.com

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Your Story...

Have you written it?
Are you ready to share?

It is generally acknowledged that writing of your experiences with your heart kid (or any other life experiences) is very therapeutic. If you have written about your heartkid, please consider submitting it for publication in our newsletter. If you haven’t written yet, you might find that writing things down helps you, and sharing your story helps someone else.

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For The Kids

Father’s Day Word Search

Words to search for:

- BOWLING
- BREAKFAST
- DAD
- DINNER
- FISHING
- GIFTS
- JUNE
- KIDS
- LOVE
- PARTY
- TEE SHIRT
- YARDWORK

Find Garfield’s sunglasses

colour in...
Hi Everyone

WOW what a stressful time! As of yesterday exams are over (thank goodness!), and its time to go back to school. I never actually thought that I’d ever look forward to class, but now I would choose a regular school day over an exam break without hesitating at all! I hope everyone survived the study cram like I did, and those that don’t have exams as of yet all survived the general stressful atmosphere that can be found at school.

I am a little bit sad however, that nobody has given me anything to use for this newsletter :( I know its a busy time, but I was still able to write this column for you all! We can’t keep leaving it up to the same people... and you get PRIZES guys! Why wouldn’t you write to me if there are prizes?? I hope you all read my personal story in the last newsletter, and my theory is that everyone was so inspired by my article that you are all just taking an extra long time trying to perfect your story for me! Haha that would be nice, and I hope that I receive them all soon... but somehow I’m not so sure!

Well, as I’m writing this the Justice Crew workshop hasn’t happened, but it is only next weekend I am very excited! I will assume that it was an amazing day full of fun, and I saw lots of HK teenagers at this once in a lifetime opportunity. As those that attended will have discovered, I am a TERRIBLE dancer and I apologise for all those that had to watch me, but hopefully I did learn a little bit...

When this newsletter is released, it will probably very close to the beginning of the July school holidays, and in a few days on Saturday 9th July there will be a private movie screening at the Jaffa Room just for us teenagers!! More information can be found in the ‘events’ section of our newsletter. Previously it had been advertised that we would be viewing ‘Diary of a Wimpy Kid 2’, but because of lack of interest the movie will be changed, but at this stage I am unsure what it will be. I hope that you all take advantage of this FREE event, and enjoy the movie as well as indulge yourself with all the delicious food!

Also to celebrate the beginning of the term 3 holidays on Friday September 30th, teenage HK’s are invited to a very special hummer and dinner night! Please don’t miss this opportunity to ride like the VIP you are in a hummer limousine and then enjoy a delicious meal at a restaurant, which has not been decided upon yet, but I can imagine it will be great! Get in quick as there are limited places available but I hope that you all come along, as it will be a fun night, where you will have plenty of time to talk and catch up with old friends and make new ones!

And now, I will have to sadly end my article with a boring recipe, as no-one has written to me :( But I do hope you all enjoy these yummy pancakes, and pair them with a delicious hot chocolate to warm up on a cold winters day! Mmm...

Practically perfect pancakes

**Method**

1. Sift flour and bicarbonate of soda into a medium bowl.
2. Heat butter and honey in a small heavy-based saucepan over a low heat. Cook while stirring, until melted and smooth. Set aside to cool.
3. Add buttermilk and egg to butter mixture and whisk until combined.
4. Make well in the centre of flour mixture and add buttermilk mixture. Stir until a smooth batter forms.
5. Brush base of a medium heavy-based non-stick frying pan with butter and heat over a medium heat.
6. Pour ⅓ cup of the batter into pan and cook until small bubbles form on surface and pancake is golden underneath.
7. Flip, then cook until light golden, transfer to a warm plate, and repeat with remaining batter.
8. After all batter has been used, top with whatever you like. Some yummy ideas are maple syrup and banana, chocolate sauce and cream, honey and berries, and plenty more!

**Ingredients**

- 1 cup self raising flour
- ½ teaspoon bicarbonate of soda
- 60g unsalted butter
- 2 tablespoons honey
- 1 cup buttermilk
- 1 egg lightly beaten
- Melted butter for greasing

**Preparation time:** 15mins  
**Cooking time:** 20mins  
**Makes about 6 pancakes**
A Starlight Wish is like a dream come true for a child or adolescent with a serious or chronic condition. Sharing a special, once-in-a-lifetime wish brings a family together and is an experience that stays with them forever.

To refer a child or adolescent please complete the Starlight Wish Referral Form available at starlight.org.au or phone 1300 727 827 and ask to speak to the Family Relationship Coordinator in your state if you wish to discuss a specific referral.
### HK Birthdays

#### JULY
- **01.07.04** Molly MAWER
- **03.07.95** Daniel MEEHAN
- **05.07.04** Ruby Musca
- **05.07.92** Lachlan RUSIN
- **05.07.09** Gracy Anne BAXTER
- **06.07.81** Jason PANIZZA
- **08.07.99** Jack Barclay
- **11.07.10** Anthony Chan
- **13.07.79** Cherie NYE
- **16.07.02** Shynique BICKNELL
- **16.07.05** Cadence CARGILL
- **19.07.81** Laura MORI
- **19.07.98** Thomas VICKRIDGE
- **21.07.96** Lauren HOLMES
- **22.07.08** Chloe Poulet
- **25.07.84** Raymond NAYAR
- **27.07.88** Jenna GUTHRIE
- **29.07.07** Max Del Grossi

#### AUGUST
- **01.08.02** Teddy STANLEY
- **01.08.09** Sienna Ross
- **01.08.96** Cameron Harvey
- **02.08.02** Leecy HILL
- **02/08/95** Lucy Franklin
- **05.08.92** Cameron MC GUIRE
- **05.08.04** Aaron Lanagan
- **07.08.93** Carrie DURDIN
- **07.08.04** Liam SWEENEY
- **08.08.08** Isaiah Davison
- **08.08.09** Blake O’Brien
- **08.08.06** Brooke Trutewin
- **09.08.95** Courtney Anne GREEN
- **09.08.97** Isabella VIDOTTO
- **12.08.99** Jesse BUCHANAN
- **13.08.09** Marley PROUD
- **16.08.95** Shakira Kate DONOVAN
- **17.08.00** Nicholas LEE-STEERE
- **18.08.91** Vertly SOFTLY
- **19.08.05** Riley Hall
- **20.08.99** Alyssa DICK
- **20.08.01** Ruth HARVEY
- **21.08.01** Joshua FRANK
- **22.08.02** Lochlan WHITE
- **22.08.08** Joshua Walsh
- **24.08.00** Brodie HILL
- **26.08.94** Daniel CASEY
- **27.08.09** Joshua Martin
- **28.08.00** Julie HARVEY
- **28.08.97** Shane TOMLINSON
- **29.08.88** Rhys TOWERS
- **30.08.95** Conrad MORRIS
- **30.08.79** Jeremy SELTEN
- **30.08.05** Kobi WARREN
- **31.08.01** Sam REEVE
- **31.08.95** Rebecca SYMES
- **31.08.97** Jesse TEICHELMAN

#### SEPTEMBER
- **01.09.89** Victoria DENN
- **01.09.98** Lachlan SMITH
- **02.09.98** Paul MILLARD-SMITH
- **02.09.94** Sharyn WESTON
- **04.09.96** Jade HALLAM
- **05.09.09** Xavier Cue
- **06.09.86** David KYLE
- **06.09.95** Daniela VO
- **08.09.09** Mackenzie HEDGES
- **09.09.05** Jason Grjusich
- **09.09.09** Rufus BREWER
- **10.09.01** Erin CASTINE
- **10.09.99** Avelyn WOOD
- **12.09.02** Tyler METLITZY
- **12.09.02** William KIRKBRIGHT
- **12.09.05** Jayde GeorgiaCHRISTMASS
- **12.09.08** Sean Saunders
- **13.09.02** Angleina John-Hutchins
- **13.09.84** Eddie SCHIEL
- **13.09.96** Janelle Redman
- **15.09.95** Helena Michelle PAY
- **18.09.06** Laura Webster
- **19.09.84** Stuart GUTHRIE
- **19.09.02** Miriam MITCHELL
- **22.09.99** Sam MURPHY
- **23.09.04** Jaxon Hill
- **24.09.91** Reilly CRAIG
- **24.09.91** Kate MITCHELL
- **24.09.02** Thomas EDWARDS
- **25.09.04** Harry PARKER
- **27.09.96** Rosie BARTON
- **28.09.90** Julie YOUNG
- **29.09.99** Travis BENNETT
- **29.09.02** Darcy INGLE

### Angel’s Birthdays

Although it’s difficult today to see beyond the sorrow, may looking back in memory, help comfort you tomorrow.
Thank You!

HeartKids WA Sponsors & Supporters

Government of Western Australia
Department of Health

HKA National Sponsors

Reading someone else’s copy?

Send this enquiry slip (or a copy) to HeartKids WA and we will send you an information pack. HeartKids offers a broad range of support services, membership is free. A subscription fee of $25 pa is payable to receive our quarterly heart to heart newsletter.

Your Name

☐ Family  ☐ Adult with CHD  ☐ Interested Person

Address

Phone  Email

Heart Child’s Name (if applicable)  Date of Birth

Relationship to Child

Heart Child  ☐ Male  ☐ Female

Post form & payment to the office:
PO Box 1554,
West Perth WA 6872

OR email to:
hkwa@heartkids.org.au