



Annual Report 2008/2009



SUPPORT — AWARENESS — ADVOCACY — RESEARCH



Cover Photo - Dominic White Inside Cover - Maddison Watkins



Our Association in profile

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.**

Support

- ♥ Provide access to support services for the full journey of all those affected by CHD.
- ♥ Ensure families' travelling expenses are fully subsidised, when travelling long distances or interstate.
- ♥ Employ Family Support Coordinators in every relevant hospital and community.
- ♥ Provide medical equipment for hospitals to support the management of CHD.
- ♥ Provide a range of educational and support materials and publications for families, schools and medical rooms.
- ♥ Support outreach services to include rural and remote communities.

Awareness

- ♥ Australians will become aware of and sympathetic towards the prevalence and impact of CHD on heart kids, their families and the community and understand how they can help.
- ♥ HeartKids has a profile to match the prevalence and impact of Childhood Heart Disease.
- ♥ Increase awareness of CHD and the treatments available, leading to earlier detection and better outcomes for heart kids and their families.

Advocacy

- ♥ Partner with the medical community and researchers to lobby for improved hospital services, procedures and practices leading to a world class health system for CHD.
- ♥ Ensure policy makers understand and respond to the impact of heart disease to achieve the best possible outcomes.
- ♥ Foster and maintain partnerships with other organisations that benefit our mutual objectives.
- ♥ Strive for reduction in red tape and ensure improved levels of service delivery for children and families affected by CHD.

Research

- ♥ Use our brand as the public face of Childhood Heart Disease to significantly increase funding from individuals, corporates, State and Federal Government to increase research into the causes, treatment and management of CHD.
- ♥ As a result of this, funding for CHD research will match the prevalence and impact of CHD on heart kids, their families and the greater community leading to significant reduction in mortality and suffering caused by CHD.

Our People

Ambassadors: Simon Reeve, Dr Cindy Pan, Glenn Archer, Graham Manou, Michael Toon **State Patrons:** Ted Kitto & Prof Jim Wilkinson, VIC, Dr Gary Sholler NSW, Dr Gavin Wheaton SA, Cr Paul Pisasale QLD, John Bignell WA

Chairman: Stephen Shepherd **Vice Chairman:** Clare Fountain **Treasurer:** Ryan Payne

Directors: Matt Finnis (until Sept 08), Matt Tognini, Jean Jacques Lasm, Lee Morgan, Scott Reinke, Matthew Turner

Chief Executive Officer: Neil McWhannell JP **Chief Financial Officer:** Michelle Strawbridge

Administration Manager: Lisa White

State Managers: Dawn Everingham NSW, Tracy Stanley VIC, Fran Maunton/Karen Mason WA

Kerry Southwell SA, Janis Pratt QLD

Family Support Coordinators: Karen Sherlock & Kim Mackie NSW, Tracy Stanley & Lynette McCoullough VIC,

Kylie Bath SA, Cecilia Donovan WA, Silvia Strohr QLD

Newsletter Editors: Margaret Patullo VIC, Jo Hui NSW, Janelle Sugden WA, Jacqui Misfud SA

Directors Attendance Record; Chairman: Stephen Shepherd 100% **Vice Chairman:** Clare Fountain 100% **Treasurer:** Ryan Payne 100% **Directors:** Matt Finnis 100%, Jean Jacques Lasm 100%, Scott Reinke 100% Matthew Turner 100% Lee Morgan 100% Matt Tognini 100%



HeartKids Annual Report 2007-2008

2007 – 2008

executive reports

Chairman's Annual Report



Our annual report provides an opportunity to reflect on and celebrate the difference we are making and focus ourselves for the opportunities that lie ahead.

Why does HeartKids exist?

Childhood Heart Disease (CHD) is the greatest killer of children under 5 in Australia, taking more lives than all other diseases combined and twice that of childhood cancers.

It is the most common birth abnormality, affecting approximately 1 in 100 children, which equates to over six new babies per day or approximately 2000 per annum in Australia. Of these approximately 250 will pass away and over half will require either lifelong medication or repeated surgeries. The total number of living patients in Australia born with a cardiac defect is approximately 62,000. The number of affected family members is in the order of 1 million.

Children with heart disease fill almost half the beds in intensive care units of major children's hospitals.

In about 80% of cases the cause is largely unknown.

Despite these statistics, Childhood Heart Disease receives no Government funding and has

limited general awareness attached to it. This is where HeartKids steps in. We are Australia's only charity solely focused on Childhood Heart Disease.

How is HeartKids making a difference?

We are making a significant and increasing difference today and have big plans. By working in partnership with the medical community and government, we aim to significantly reduce the above statistics and improve outcomes and quality of life for our heart kids as highlighted in our Vision and Mission.

We are making this difference in 4 key ways:

Support

This is the core of what our various State bodies do. They employ Family Support Coordinators who, as the name suggests, work directly with the many kids and their families at major children's hospitals around the country. They support families in emotional, practical and sometimes financial ways. Last year they supported over 1000 families.

We are also delivering increased services and resources such as Family Camps, Coffee Mornings, Brochures, Educational Material, Teen Camp and online forums.

HeartKids Australia's role here is to work closely in partnership with our various State bodies to help fund and build a National support framework that is then delivered by the states in their local communities. We plan to significantly increase these services over the next 18 months.

Awareness

As mentioned above, for some

reason this is the hidden disease. Unlike other childhood diseases, Childhood Heart Disease has limited public profile and brand. Whilst this remains the case, funding and investment in appropriate research, infrastructure and services for our heart kids will continue to be limited.



Hayden McConnachie

We are in the process of changing that with events such as our Tiny Tickers Balls, National Cuppa for Kids program, whilst increasing television coverage on shows such as Dancing with the Stars and 60 minutes all help.

Earlier this year we commissioned Professor Sandy Leggett to complete a research and discussion paper on Congenital Heart Disease. Upon release later this year, this paper, which has had significant input from leading clinicians, will highlight the stark statistics of the disease and what the needs are, both from a clinical, research and community perspective.

Advocacy

Working closely in partnership with the medical community and via our

planned commissioning of further research, we are seeking to determine where the greatest need for structural and policy change is, so that we can increasingly engage our State and Federal governments in the goal of identifying and implementing world's best practice.

Research

Despite Australia having some of the world's foremost practitioners, medical research into Childhood Heart Disease is woefully under funded. Last year with the generous support of corporate sponsors such as Manchester Unity and Pasta Master, HeartKids contributed approximately \$300,000 to various research projects. We hope to significantly increase this in coming years.

A dominant theme in these objectives is to expand our support services to meet the needs of

people affected by CHD throughout the entire journey of their lives. This focus will be the theme of our National Conference and will provide clear goals and performance targets.

Focus for 2009 / 2010

- Continue to position CHD as a major issue requiring additional support.
- Utilise Professor Leggat's paper to help form consensus as to structural and policy change needed to positively impact our heart kids and their families.
- Grow and strengthen our local communities and partnerships
- Significantly increase our support services

As highlighted above and in the CEO and Treasurer's reports, the past year has been one of significant growth and maturity of our organisation.

I would like to thank our National Board as well as our National Team Neil McWhannell, Lisa White and Michelle Strawbridge for their dedicated efforts in achieving these milestones. I was delighted that Neil was awarded the Equity Trustees, First Year Achiever Award at the National CEO of the Year function. This was well deserved and has provided significant exposure and opportunities for HeartKids.

Our organisation is now positioned well to continue to make a huge difference in the lives of heart kids and their families.

Stephen Shepherd
Chairman
HeartKids Australia

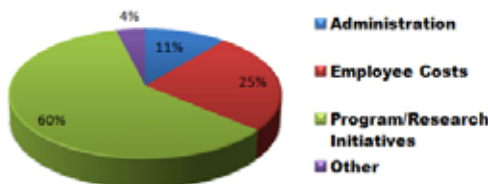
Treasurer's Annual Report



HeartKids Australia completed the year in a relatively strong financial position, despite the tough economic times which increased the challenges of obtaining support from donors.

Major additional expenditure was incurred as a result of commissioning the White Paper and attendance at the World Congress, yet we still achieved a healthy surplus of \$54,290 and net assets increased considerably by 29.5% to \$238,257. During the year, the significant revenue streams from Manchester Unity, Pasta Master and Beaver Machine Corporation continued. A major achievement was securing funding of \$45,000 from the Newman's Own Foundation and Roche Diagnostics to fund the 2009 Teen Camp.

Expenses 2008/09



Approximately \$300,000 was expended on our various research grants in 2008/09. A full report on these are shown later in this report. We were also pleased to have been able to offer significant tangible support for HeartKids activities in each of the States. This included \$50,000 which contributed to the funding of state based family support workers, as well as \$5000 towards emergency family assistance.

In addition we provided all insurances and developed a wide range of resources and materials. We were also delighted to see how Heartkids South Australia developed as a result of the seed funding provided in 2007/08.

A new direct mail campaign was launched during the year. This produced disappointing financial results, however excellent results are anticipated early in the new financial year with the "Cuppa for Kids" campaign. This is already showing signs of great support and will result in a considerable growth of the donor database.

Special thanks are extended to Michelle Strawbridge for her work as CFO. A significant initiative this year was the collaborative work being carried out by her and the State Treasurers to ensure consistent and appropriate financial management practices are in place.

With our organisation currently experiencing much greater levels of exposure and support, our goal of expanding our support services looks to be a realistic and exciting one.

Ryan Payne
Treasurer HeartKids Australia
Chair HeartKids NSW

Income 2008/09



Chief Executive Officer's Annual Report

This past year has been one of continued growth for HeartKids. With the national entity up and running we have developed a range of initiatives that not only serve the state organisations, but assist in improving our efficiencies and effectiveness and develop us as a true national entity.



CEO with Phil Riggio at Kiwanis Convention

Strong financial position and reporting

As shown in the Treasurer's Report, the organisation has made significant progress in establishing a sound financial base from which we can now confidently grow and expand our support services. It is anticipated that, in coming years, this will result in increased support to each State and to their various operations.

States have also worked with our Chief Financial Officer to ensure we develop uniform financial management systems. This has allowed us to gauge the financial health of our organisation and develop appropriate risk management strategies. Some States have also decided to employ the CFO to manage their finances.

Positioning exercise completed

With the help of Director Scott Reinke, a comprehensive study on our positioning and branding was completed which will serve to guide us in the way we present ourselves to become a significant children's health charity.

National Database established

A national database system was established through the generous

support of the Salesforce Foundation. This system will allow us to better serve our members whilst being able to appreciate the full national needs of Childhood Heart Disease (CHD). The system will also allow us to record details of all donors and supporters thereby enabling us to more effectively manage new initiatives and activities.

Membership review

Many States also undertook a review of their membership options with the intent of making our services more available to everyone affected by CHD. The result of this has been very positive with a significant rise in families being supported. This has in turn seen more people engaging with and supporting our activities.



Chelsea and Amelia Mason

Commissioned independent White paper on Children's Heart Disease

One of the key activities in the year was the decision of the Board to commission an independent review into the whole area of CHD. This review in the form of a White Paper set out to determine exactly what the current national situation was and compared this to other leading countries. It also looked at the clinical and community needs of CHD. This involved Dr Sandra Leggat, Professor Health Services Management, Head of School of Public Health at La Trobe University, who carried out the review, interviewing leading

clinicians, surgeons and researchers across each State.

In addition she interviewed all the Family Support Coordinators and some parents of children with CHD.

We are most grateful for the support of Actelion Pharmaceuticals in assisting with funding for this project. The paper has just been completed and we are now working with the pediatric community to examine how best to launch this.



Makayla from Darwin

Teen Camp Reactivated

This year we were also delighted to re activate the annual Teen Camp. With the help of the Newman's Own Foundation and Roche Diagnostics, we were able to fully fund teens from across the country to gather in Kyneton, Victoria. The event was a resounding success and plans are already underway for next year's camp which will be held in Queensland.

Developed National Fundraising Strategy

During the year we completed a Fundraising Strategy which saw us develop a range of activities and options for donations. As part of our work with this we developed and trialled a Direct Mail campaign. Unfortunately this coincided with the Victorian Bush Fires and a downturn in the world's economy so results were a little disappointing. Following this we also looked at a national program and the Cuppa for Kids concept was developed. After receiving endorsement from the

Prime Minister, we saw the potential for this activity to have a major and positive impact on awareness and fundraising. We were also then fortunate to gain endorsement from the Governor General, Leader of the Opposition, Health Minister, State Premiers along with scores of other celebrities.



Calista Chua

At the time of writing this report the program is well underway with significant registrations coming in. It is hoped to further refine and expand this concept in coming years, as it has the potential to fund expanded support services as well as serve as a great vehicle for generating public awareness.



Expanded funding and infrastructure support for our State bodies

HeartKids Australia has continued its work to provide a range of additional benefits and services to the various states. These include:

- \$50,000 funding of the Family Support Coordinators

- \$10,000 funding for Family Assistance Program
- \$45,000 for Teen Camp
- New brochures and presentation folders
- Provision of Software and web support
- Management of the vending program – now bringing in over \$100,000 per annum
- Provision of National insurance cover for Workers, Volunteers, Directors and Public Liability
- Provision of Database system
- Provision and management of teleconference facilities
- Development of new parent resources
- Subscription to online detailed Heart Condition site for parents

Expanded Support for Research

Over the past 12 months we have significantly expanded our support of research projects, with financial assistance now being offered to four projects. These include major projects being run out of the Kids Heart Research Centre, Murdoch Children's Research Institute, a cardiomyopathy study being run out of the Royal Children's Hospital and the GECHO project for indigenous children affected by rheumatic fever. Smaller amounts have also supported nursing programs in the Pacific. These total almost \$300,000.

Grown our corporate and volunteer support base

We continue to be most grateful for the support offered by Pasta Master and Manchester Unity (now a subsidiary of HCF) Their support has been pivotal in allowing our fledgling national charity to prosper.

In addition, we acknowledge the significant support offered by Watershed Wines, ID Studios, KAU Designs, Still Moving Designs, Roche, Actelion, Newman's Own Foundation, Beaver Machine Corporation, Dilmah Tea, Clayton Utz, Kiwanis International, Alpine Nurseries, Qantas, The Mortgage

Gallery, ASDM and the Vodafone Foundation.

One of the really pleasing outcomes of the year has been the number of people and companies offering to assist us build capacity and provide volunteers. Many of those arose from various television interviews and media articles highlighting HeartKids and CHD. The activities and benefits of these are too numerous to mention in full, but to all the people who have generously offered their time and talents we extend our grateful thanks.



Tom Collins

My thanks are extended to the National Board Directors, each of whom has committed themselves so positively and selflessly to supporting me, HeartKids and developing the foundations for our future. Special thanks is also offered to our Chair, Stephen Shepherd, who has led the Board with incredible skill, professionalism and dedication.

I would also like to extend thanks to the many staff and volunteers who work so tirelessly and with such incredible enthusiasm for our cause. These people make a real and tangible difference to families and children affected by CHD.

Neil McWhannell
Chief Executive Officer
HeartKids Australia

HeartKids Supporting Research

HeartKids is pleased to report on the progress made from its support of research into Children's Heart Disease. Our support is provided in the hope that fewer children will be born with CHD and that mortality rates decrease.

Genetic Determinants of Congenital Heart Disease

Kids Heart Research, The Children's Hospital at Westmead, Sydney.

The past 12 months have been a very busy time for Kids Heart Research both in terms of managing many new projects as well as preparations involved in hosting the 5th World Congress of Paediatric Cardiology and Cardiac Surgery. This was held in Cairns, in June and was an excellent opportunity to network with other genetic researchers working in the field of congenital heart disease (CHD).

In March 2009 we farewelled the HeartKids Australia Research Fellow, Dr Giorgia Esposito, who commenced her time with us at the beginning of 2008. Dr Tanya Butler who has been with the group from the inception of our genetics programme has taken up the post of HeartKids Research Fellow. Dr Butler's role has been restructured to focus on this important research area.

The DNA Bank, continues to grow at a rapid rate thanks to the ongoing efforts of Gillian Blue, our Genetic Counsellor, and the patients and families passing through the clinical service of the Cardiology Department. In the past 6 months we have been approached by numerous investigators requesting access to DNA samples for research into the genetics of CHD. This has led to collaborations between our group and prominent research groups both within Australia and internationally and I will briefly summarise and update you on these.

In-house Studies and Collaborations

A study initially set out to investigate the findings of a research group in Germany on somatic mutations in patients with congenital heart disease has led to collaboration with Dr Paul Grossfeld, a Cardiologist at the UCSD Medical Cen-

tre in San Diego, California. Although our findings indicate that somatic mutations cannot account for most cases of CHD in DNA derived from patients with Tetralogy of Fallot (TOF), we did get some interesting results on the samples derived from patients with hypoplastic left heart syndrome (HLHS). Dr Grossfeld has a particular interest in HLHS and has contributed a number of tissue samples to expand our HLHS cohort and allow us to investigate this further.

We are currently involved in a number of collaborative studies with various researchers both local and international. We have recently collaborated with A/Prof Diane Fatkin from the Victor Chang Cardiac Research Institute on a preliminary study looking at a candidate gene involved in patent ductus arteriosus. We are also planning to publish the findings of a collaborative study with Prof Richard Harvey from the Victor Chang Cardiac Research Institute on the GATA4 gene, which is well known for its involvement in heart development.



Ass Prof David Winlaw and Dr Tanya Butler

An exciting new development is the proposed collaboration with Prof Jianjie Ma, an eminent researcher in the field of cardiac physiology in Boston. This project would bring together Surgery and Intensive Care at the Children's Hospital at Westmead with this international group. Clinical outcome after open heart surgery will be the topic of the investigation with a focus on genetic susceptibility to poor post-surgical recovery involving a membrane repair protein.

Multi-centre Studies and Collaborations

We are currently participating in 2 international, multi-centre, large-scale studies looking for new genes involved in congenital heart disease. The first (CHARTed) gained funding approval late last year and commenced in January 2009. We have been busy selecting appropriate samples for participation and are looking at dispatching them to Europe, where they will be analysed, within the next 2 months.

The second study has received funding from the Wellcome Trust in the UK and we are contributing thousands of DNA samples from the DNA Bank to this study. We expect to have the samples selected and prepared within the next few months.

Other Interesting Developments

Kids Heart Research has been invited to contribute to working group discussions to support The Australian Children's Clinical Trials Centre. We will be actively involved in two areas; one focusing on aspects of electronic management of clinical trials activities and the other considering Bio-banking needs and strategies. Our experience and systems, generously supported by HeartKids, will be valuable to these discussions to drive research advancing improved clinical care of children.

In summary, the past twelve months have been very exciting for Kids Heart Research with many new prospects on the horizon. It has however also highlighted the enormous cost of running and maintaining this precious resource in order to provide the high quality required for both local and international collaborations as well as our own in-house research. Thank you to HeartKids Australia and their sponsors for their continued support of this work.

Ass Prof David Winlaw
Head, Kids Heart Research

Clinical study of remote ischaemic preconditioning. Murdoch Children's Research Institute.

Primary aim:

To determine if remote ischaemic preconditioning reduces troponin I levels measured 6 hours post-operatively in two groups of patients undergoing cardiac surgery.

Secondary aims: 1) To describe the potential modification of the systemic inflammatory response. 2) To describe the potential modification of cardiopulmonary bypass induced lung injury.

Since the last report, there has been progress in a number of areas.

Clinical study of remote ischaemic preconditioning.

Eighteen patients have been recruited so far to the project. The data will not be examined until there are more patients. We have had no adverse events with the study to date.

Animal study of remote ischaemic preconditioning.

We have completed an animal study examining the effect of inducing remote ischaemic preconditioning 24 hours prior to the regional ischaemic injury (ligation of a coronary artery for 40 mins) in a sheep model of myocardial infarction. The data have not yet been fully analysed but the earlier induction of protection seemed to be equally effective in reducing the amount of tissue death but did not provide any added protection against heart dysfunction.

Planned studies.

We have ethics approval for a study to examine the effect of remote ischaemic preconditioning in a sheep model of cardiopulmonary bypass (heart lung bypass) which we use routinely to support the circulation during open heart surgery. In this study we will compare the effects of early (immediately before) and delayed (24 hours prior) remote ischaemic preconditioning. We will also use a novel drug which may have similar effects in heart protection.

Many thanks to HeartKids for their ongoing support of this exciting research project.

Dr Michael Cheung – Consulting Cardiologist, Dept of Cardiology, Royal Children's Hospital and Murdoch Children's Research Institute

Cardiomyopathy Study

In late 2008 we began supporting an additional research project being conducted by A/Prof Rob Weintraub at RCH. The funds provided are assisting him to complete an existing project in which he has been compiling registries for children with chronic and serious medical heart conditions.



Ass Prof Dr Rob Weintraub

These serve both clinical and research purposes: By gathering together patients with similar conditions he can provide specialty clinics which allow patients access to new developments in molecular genetics, cardiac imaging and medical management.

His registries allow him to describe these medical conditions in more detail, including causes, outcomes, response to therapies and quality of life. Because the registries cover entire geographical regions, the information he acquires has an impact that exceeds traditional studies arising from single institutions.

Each registry requires a purpose built database and a registry manager. Some of this work is already funded with the remainder funded with whatever resources are available. The associated

expenses which include site visits, statisticians and epidemiologists, are invariably greater than the amount of available funding. HeartKids funding is covering these additional associated expenses.

Project GECHO

This project with the anagram made up of the title Getting Every Child's Heart Okay is being run by Prof Jonathan Carapetis based out of The Menzies School Of Health Research. The project has been looking at the hearts of indigenous and Torres Strait Islanders .

The Rheumatic Heart Screening Project, in the NT, is checking the hearts of 2000 young Aboriginal and Torres Strait Islander Children in remote communities and 500 kids in town.



Dr Jonathan Carapetis at one of his clinics

Rheumatic Heart is the most common acquired heart disease of children worldwide. Australia has some of the highest rates of incidence in the world in our indigenous communities. Yet this is a preventable disease often resulting from untreated skin lesions and strep throat.

The project is seeking to:

Find out the extent of the problem
To confirm that echo is the best way to make the diagnosis of Rheumatic Heart Disease (RHD) to identify kids with early RHD, before they are sick and when prevention works best.

To assist with education and prevention.

This project has been generously supported through the efforts of Kiwanis International who are working with HeartKids to assist Dr Carapetis and Dr Wheaton in their work.



2008 – 2009 executive reports

HeartKids VIC Annual Report

Heartkids Victoria has continued to provide a broad range of services to its members, as well as make some significant progress in developing its marketing and advocacy activities.

This year saw HeartKids Victoria move to offer free membership. We are keen to ensure that all those affected by CHD can be helped and supported by HeartKids, without any barriers. As a result of this we have been seeing our membership numbers steadily increase, but we want more, and we want to be able to know that we are representing the entire CHD community - of all ages.



Kellin Hyde

With a Board member dedicated to Volunteers, we have been working to recruit a larger number with a broader range of skills to help HeartKids. As a result we are now providing a broader range of support activities for our members and the team is growing.

HeartKids Victoria hosted the annual HeartKids Australia Teen Camp this year again. It was a terrific event with 80 teenagers and 25 supervisory staff attending for

three days of activities at the Campaspe Downs Country Resort in Kyneton, Victoria.

With the great support provided by our friends at Kiwanis we were also able to offer our families a Spring Family Camp in Healesville, the Deni Camp, a Shepparton Picnic event, the Box Hill Little Trains Day and a Myuna Farm Day. Other Support events included tickets to Circus Quirkus (provided by local businesses and the Rotary Club of Preston) as well as a great Magic Show, and a Give It a Go Day - this day allowed our members to have an active day out with lots of fun activities and the opportunity to watch Bindi Irwin in concert.

This year saw us launch a new look Newsletter. Not only is it a cleaner and more professional publication, but we were most fortunate to have Fishprint printers and Raleigh Paper come on board as sponsors of our newsletter. This was a significant support and we are very appreciative to have them join our support team. What's even more special is our newsletter is fully environmental friendly, printed with environmentally safe inks and on paper made from sugar-cane waste, which is also very eco-friendly.

For fundraising, we are very fortunate to have great friends and supporters such as the Northern Service Clubs, (Kiwanis and Rotary) who put on their regular HeartKids Spectacular raising a terrific amount; and the Nelson Alexander Foundation, who donated the full commission from the sale of one of their properties.

Unfortunately last winter saw our surgery cancellations rise and cause a great amount of anxiety and difficulty for so many of our parents. However through this adversity I am pleased to say some

good did come. The Herald Sun picked up the issue, and working with HeartKids we saw a full front page feature on the plight of our children and families on the 26th and 27th August. As a result, a huge amount of media followed and three days after the first front page article appeared the Health Minister announced a number of initiatives to reduce the problem.



Mia Cowley with Santa

With a new children's hospital being built, we continue to work with the Royal Children's Hospital to try and ensure the new facilities will best meet our member needs for today and the long term future. While it will be a wonderful environment we must ensure that it has the best infrastructure possible, not only for Victorian heart children, but for the hundreds of interstate patients that are treated there every year. The RCH undertakes all significant complex cases and is the only one performing transplants in Australia.

With a new Events and Communications Manager on board, Sharon Elder, we now have a significant range of events planned for next financial year that will greatly assist HKV raise its profile in the community as well as raise much needed funds to support our work.

Next year will be an exciting, busy and I believe very successful year for HeartKids Victoria

Scott Reinke
Chairman - HeartKids Victoria

HeartKids Queensland Annual Report

It has been a very busy year for HeartKids Qld.

Recently we have seen 10 Good Guys Stores join Robina Good Guys, in supporting HeartKids Qld as their charity of choice via their Community Gives Program. We see this as a great opportunity to raise the awareness of HeartKids in the Brisbane Metropolitan Area along with the Gold & Sunshine Coasts. Our newly expanded relationship with The Good Guys has allowed us to spend \$10000 on much needed bedside heart, blood oxygen monitors, for the children's ward at the hospital. We are now investigating what other additional family support services and equipment we can provide for the Cardiac Ward, with the remaining \$40,000 which should come in over the next 12 months. HeartKids Qld Inc would also like to thank James Home Services and Manchester Unity for their continued financial support, over the past 12 months.



Airen Youhanna and heart kid Riley

2009 "With all our Hearts" Calendar – This year's calendar was a great success with a net income of \$25,000 being received. Not only did this initiative raise a great amount of funds, it also allowed Heartkids to get their name out into the community.

Children's Cardiac Ward, Mater Children's Hospital – It has been 12 months since the Queensland Cardiac Pediatric Service (QPCS) moved from the Prince Charles

Hospital to the Mater Children's Hospital in readiness for the move to the Queensland Children's Hospital (QCH) in approx 2012. We have had an increase of members into the charity and this could be attributed to the fantastic working relationship we now have with the QPCS. The great atmosphere within the service is thanks to Silvia's enthusiasm and commitment to HKQ.

Sing & Grow Music Program – This fun program is being held at the Mater Children's Hospital for heart kids, siblings and parents. It has been huge success and will now become an ongoing activity. HKQ are providing free parking for parents as well as morning tea for the participants after the completion of the classes.

The Prince Charles Hospital commemorative statue - On the leaving of the QPCS & HeartKids from the Prince Charles hospital and considering our joint history we decided to commemorate the big move with a memorial statue. HKQ co funded this project with Qld Health and established a beautiful statue to commemorate our time with the hospital. The statue titled "Passage" is a great symbol of HeartKids passage through the hospital over the last 30 years.



Passage Statue

HKQ Patron - Councillor Paul Pisasale, Mayor of Ipswich City has with much excitement (on his and our behalf) agreed to be the HKQ State Patron. We are looking forward to working with Cr Pisasale in increasing the awareness of HeartKids within the community and raising much needed funds.

In the coming 12 months HeartKids Qld are looking at expanding our support and advocacy programs to include the following;



Hayden McConnachie

- Developing more Family Support Programs to benefit heart kids and their families.
- Increase the hours of the Family & Advocacy Program, which we provide at the hospital.
- The establishment of a Parking Initiative, to help long stay heart kid families.
- Improved catering and support for the parents lounge at the hospital.
- Further development & support of Kidz4Heartkids and the Adult Heartkids Group.
- The development and implementation of more activities and events, to create better awareness of Heartkids in the greater community.

HeartKids Qld Inc would like to thank all the corporate & community groups who have supported us this year. We would also like to thank all the people within the general community and HeartKids parents, who have volunteered their time in either fundraising or support, to help HKQ deliver benefits and services to HeartKids and their families in Queensland.

Thank You for your Support

Janis Pratt
State Manager HeartKids QLD

HeartKids NSW Annual Report

HKNSW continues to make a positive impact on the lives of families who are dealing with CHD.

Our Family Support Program with Karen Sherlock and Kim Mackie firmly at the helm, continues to do a fantastic job in supporting our families both in hospital and at home.

Our organisational services run by Dawn Everingham, Elizabeth Taylor and Mary Bowie essentially keep the organisation running smoothly with their operational skill and fundraising abilities.

Our Events Manager Mary Bowie organised many events for us including a truly amazing 2008 Tiny Tickers Ball held in September which over 500 attended and which raised over \$100,000.



Mark Beretta, Kerri Pottharst Wilding,
Sarah Groen, Ryan Payne

We are very proud of the work contributed by our wonderful board, their team work, commitment and dedication to our cause is astounding.

At our Strategic Planning Day we set many long and short term objectives.

To assist the board in developing these a comprehensive member survey was conducted—results of which are on our website.

HeartKids NSW was involved in some very successful fundraising events over the past year. These included 2

Trivia nights-at Manly and Penrith, which raised a total of \$22,000.

FMA Golf Day- held at Bonnie Doon Golf Club. HeartKids were invited to promote our cause and accept donations, in total \$1500 was raised.

HeartKids Hillclimb- the inaugural event was organised by Daniel Cummins, a member from ACT. This proved to be a fantastic event to raise awareness in the Canberra area. In addition to this, over \$3500 was raised from raffles and donations. Westpac Bank generously matched this figure.

Grants-Perpetual Foundation have generously agreed to fund our Family Support Program for the third year. In addition, the St George Foundation has funded our Family Assistance program to include vouchers for meals, petrol and accommodation assistance to families in more remote areas of NSW.



Family Camp

CareBags- B.I.C have been supplying these for our families in both Children's Hospitals. These bags contain essential items like, toiletries, stationery and food items.

Blackmore's Running Festival-HeartKids NSW was chosen as an official partner charity in this year's Sydney Fun Run.

In partnership with supporting organisations, HeartKids has been able to provide the following services to our members in 2008/09.



Kim Mackie offering special FSC support

Family Support – We have been able to support 2 FSCs, based at the 2 Sydney Children's Hospitals

to support NSW families as they come to the hospital for their medical appointments. We are extremely grateful for the Perpetual Grant that has made this possible in 2008/09.

Family Camp - held once again at Mowbray Park in March. 20 Heart-Kids families attended this fantastic weekend where they had the opportunity to meet other Heart-Kids families and participate in the many fun activities the Farm has to offer. There were pony rides, whip cracking, billy tea, milking a cow and the highlight of the weekend was the Bush Dance where many of our members displayed their musical talents.

Teen Day- we invited our teen members from across NSW to attend a fun day out with others in a similar age bracket who can relate to the many difficulties in growing up with CHD. They were treated to a day at Sydney Aquarium in Darling Harbour and were also provided an iPod shuffle as a special gift.

Meal, Petrol and Accommodation Assistance Our Family Support Coordinators provide meal vouchers for both children's hospital, petrol vouchers and accommodation assistance for families from rural NSW. This is possible through the support of St George Foundation and the Manchester Unity family.

Christmas Party –every year we have a Christmas party for our Sydney based members as well as in our regional areas. This allows the families to relax and enjoy the day meeting other HeartKids families.

Newsletter- this continues to be an invaluable service for our members. Jo-Anne Hui, our editor and Ian Chong, designer do an amazing job each quarter with our newsletter and we thank them for their dedication and hard work.

We would not be able to continue our work in supporting our members without the assistance of our many volunteers. Our heartfelt thanks go to these wonderful people who make such a huge positive difference to so many other people's lives.

Dawn Everingham
Operations Manager HeartKids NSW

HeartKids SA Annual Report

It has been another very busy year for HeartKids SA, with the focus on the expansion of our support programs, increasing awareness and the building of local fundraising projects. A staggering 70-80% of SA families who require treatment for congenital or acquired heart disease must travel interstate to receive treatment, so the challenge to HeartKids in South Australia is to provide the right support that these families need throughout their life journey with childhood heart disease.



Morialta Trust presentation at Xmas

Expansion of Support Programs.

2009 saw the introduction of new support programs and the expansion of key existing support programs for families in SA. The Financial Assistance Scheme was launched in November, enabling South Australian families to claim back some of the cost of their accommodation expenses whilst they are away from home receiving treatment. February saw the doubling of the Family Support Coordinators hours allowing HeartKids to service more families in SA.

A second playgroup south of the city was created providing a place for heart kid families to get together. These programs were created and bolstered through the recruitment of volunteers and the deployment of funds raised through our fund raising programs. These programs provide much needed psychological and financial support to heart kids and their families. The challenge for South Australia over the coming 12 months is to expand these services further into other country and rural areas.



City Bay Group

Patrons and Ambassadors.

HeartKids in South Australia was proud to announce the appointment Dr Gavin Wheaton as the inaugural patron of HeartKids in South Australia. Dr Wheaton is a pediatric Cardiologist, the Medical Director at the Women's and Children's Hospital and a great supporter of HeartKids. HeartKids also announced Graham Manou and Jacob Holmes as ambassadors in South Australia. Graham is the captain of the South Australian State cricket team, the Redbacks, and is currently a member of the 2009 Australian Ashes Team. Jacob Holmes was a member of the 2006 men's basketball team who won gold at the 2006 Commonwealth Games and is a member of the Adelaide 36ers basketball team.

Sponsors and Supporters.

Nationally, Manchester Unity and the Beaver Machine Company have contributed to the support programs operated in South Australia. Locally IKEA in South Australia has been a fantastic



Dr Gavin Wheaton and Adelaide Fringe Festival Director Christie Anthony

supporter of HeartKids over the past year and have committed to continue to support HeartKids for a further twelve months. The Morialta Trust are a major funding contributor to the family support

program for HeartKids, enabling the expansion of this support program. HeartKids of South Australia is also being supported by the Channel 9 Telethon and the Queen Adelaide Society.

Fundraising and Events.

The fundraising and events subcommittee have worked tirelessly over the past twelve months to raise awareness and much needed funds for the local organisation. Local events included;

- City-Bay Fun Run
- Adelaide Fringe Festival
- Quiz Night
- Christmas Family Picnic
- Teen Camp
- IKEA Ball Room Party
- Mother's Day Dinner

I would like to thank our staff, my fellow HKSA Committee members, and all those who have worked tirelessly to support our organisation and its cause. Sincere thanks also to those who have provided us with the much needed financial support that enables us to support those families who are affected by childhood heart disease.



Sadie and Ava, Christmas Picnic

Matt Turner
Chair-HeartKids South Australia
Director – HeartKids Australia

HeartKids WA Annual Report

HeartKids WA had a major change this year with the long serving Manager Fran Maunton finishing this position after approximately 15 years of service. HKWA appreciates the valuable contribution made by Fran over these many years.

I commenced as the new State Manager in March 2009 and look forward to continuing the amazing work of this great organisation.

The highlight of the year was the HeartKids Gala Ball at The Sheraton Hotel in March which raised almost \$80,000. Our thanks to major event sponsors Entrust Private Wealth Trust, The Mortgage Gallery, IKEA and Watershed Wines. John Bignell from the Mortgage Gallery was honoured as a Life Member of HeartKids WA for the outstanding support he has given over the past 5 years.



Family Camp

John's first contact with HeartKids was in 2004 when he saw the Butterflies DVD at a Football game and was compelled to act. He is an outstanding role model for corporate sponsorship and his example has encouraged many individuals and companies to be generous.

HeartKids Geographe also held a successful Ball at Watershed Winery in Margaret River with special guest Ernie Dingo as MC. This event raised \$25,000 which will be used to purchase equipment and support hospitals in the Geographe Region.



Paddy

The strength of HeartKids WA is in family support and the fantastic activities and events that are held throughout the year. The monthly Coffee and Chats, bereavement meetings, and much appreciated pamper days for our amazing Mums provide invaluable support and encouragement. Parents have especially appreciated the Special Condition Coffee and Chats to connect with other parents whose children have the same heart condition and receive input from cardiology staff.



Horse riding at the Family Camp

Our incredible Support Coordinator, Cecilia Donovan has also hosted fun events including Rock Climbing, Dads' Golf Day, Penguin Island Trip and a Kid's Day at IKEA's Smaland. The Family camp was attended by 30 HeartKids families with fantastic feedback especially about the pony rides, Hot Rod Cars, sports clinic and puppet show. Harley Davidson rides were also enjoyed by all!



Snakes alive — Family Camp

We have enjoyed a close working relationship with the cardiology staff at PMH which is essential in providing the highest level of support to our heart kids. We have also been able to help fund PMH nurses to attend Operation Open Heart in Rwanda where 24 heart operations were performed over 5 days. HKWA was able to sponsor four cardiology staff to attend the World Congress of Cardiology in QLD.



Face painting at Family Camp

In moving forward, our challenge will be to increase awareness of HeartKids in the WA community and to increase our level of sponsorship and financial support. We have recently partnered with a new corporate sponsor, GT Media, and are working on strategies for this purpose.

Despite having limited resources, our 3 part time staff with the help of the Board and volunteers make an outstanding contribution to HeartKids and must be congratulated for all that has been achieved in the past year. We look forward to growth and expansion in the future.

**Karen Mason
State Manager**

Teen Camp 2009

The 2009 HeartKids Teen Camp was held over the Australia Day long weekend from Friday 23rd January – Monday 26 January 2009.

The Teen Camp brought together 80 teenagers and 25 supervisory staff for three days of fun filled activities at the Campaspe Downs Country Resort, Kyneton Victoria and was made possible through the generous support of Newman's Own Foundation and Roche Diagnostics.



Claire, Leah and Isabella

Teenagers came from right around Australia and ranged in age from 12 -20 years.

The aim of the camp was to provide the teenagers who are experiencing the incredible trials of living with heart disease the opportunity to meet with others and to receive support from the

Teen Camp



HeartKids organisation and its large team of volunteers.

The 2009 Teen Camp was a resounding success in every aspect. Many new friendships formed and a lot of them discovered other teenagers with very similar conditions and circumstances to themselves.

For many teenagers, the 2009 Teen Camp was the first camp they had ever been allowed to attend, due to the complexity and seriousness of their heart condition and the inability or unwillingness of their school to let them participate in their camps.

One teenager who had been hospitalised for the past 8 months was given the all clear to attend and you could not wipe the smile off his face.

HeartKids Australia provided all teenagers with the best possible care required. There were 25 highly trained volunteer supervisors in attendance including doctors and nurses from the Royal Children's Hospital Cardiology department. The medical team administered all medications and provided a highly safe environment for the teenagers.

The camp provided the teenagers with a variety of activities. Activities included;

- Horse riding
- Rock-climbing and Abseiling
- Flying Fox and Low Ropes
- Trampolining and golf
- Archery
- Canoeing and Raft Building
- Meditation and Segway Mobility Rider
- Trivia Night, Movie Night and Games Night
- Indoor Swimming Pool
- Video Diary Room

The 2010 Camp is to be held in Brisbane and demand for places is already strong.

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Partners

HeartKids acknowledges the support and sponsorship from the following organisations who have offered significant support this year.

