ANNUAL IMPACT REPORT 2016-2017



Supporting heart kids through life

HeartKids is the 'compass' to help you navigate your congenital/childhood heart journey throughout your lifetime.

Hamish age 4

Vision Supporting heart kids through life

Purpose

Values · Care Collaborate • Lead • Perform

Guiding Principles

 Person and family centred Evidence based and informed Collective action Addressing health inequities Accountable governance Wellness focus Sustainable



HeartKids is committed to providing support throughout the whole life journey of the 64,000 Australians living with congenital/childhood heart disease.

WHO WE ARE

We are HeartKids, the Australian Childhood Heart Disease Foundation, dedicated to supporting all infants, children, young people and adults affected by congenital/childhood heart disease.

We fund life-saving research and give comfort through quality assured information and advice. We are the national voice and advocate for all those impacted by congenital/childhood heart disease.

Our support is a commitment for life, because there is no cure.

With advances in surgery, medicine and treatment, infants are now living longer and healthier lives which brings new challenges. HeartKids is the only organisation in Australia dedicated to bringing solutions to these challenges through Advocacy, Information, Research and Support.



OUR IMPACT

ADVOCACY

Breakthrough commitment from Australian Government for HeartKids to develop Australia's first ever CHD Action Plan



provided input to via 10 focus groups

SUPPORT

25% more families supported than last year

22 HeartKids Support Coordinators supported **11,035** individuals in hospital and in the community

Support Coordinators consist of 90% heart kid or heart angel parents and include five nurses or paramedics and four credentialed social workers.

\$235,000 of financial assistance was distributed to Australian families \$65,000 more than last year

1135 Care Bags were distributed to families 847 active volunteers helping us achieve our Vision

NEW HeartKids Family Coping Program in pilot phase with 97% of families participating rating the project as having a significant impact.

INFORMATION



NEW website and online resources for families



website last year

NEW centralised referrals directory to drive the 1800 HeartKids Helpline



referrals to other support services

NEW teen transition strategy in development to support young people on their journey into adulthood

12 new factsheets developed to help parents, young adults, family and friends to navigate their CHD journey

> **235** teenagers supported via teen transition and teen camp



7 NEW research projects funded to the value of **\$289,951**

Total of **\$1.4 million** funding towards 34 Grants-in-Aid projects to date

Total of **\$3.5million** funding across all research initiatives to date

Our funded research has attracted a further **\$1.1million** in government funding

1990 people have registered for the Australia's Congenital Heart Disease Survey



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WHAT IS CHILDHOOD HEART DISEASE?

Many people are unaware of congenital/childhood heart disease and its prevalence in Australia. Some remember the term "Blue Baby" and "Hole In The Heart Baby" - these are terms that describe congenital/childhood heart disease that in reality covers a wide range of conditions.

At HeartKids we also support children and young people who may acquire heart conditions such as rheumatic fever and Kawasaki's Disease therefore we often refer to childhood heart disease that also incorporates heart disease acquired during childhood.

Congenital heart disease is the most common congenital disorder in newborns. The birth rate prevalence of congenital heart disease is understood to be approximately 8 – 10 cases per 1,000 live births. In Australia, there are approximately 300,000 registered births per year resulting in 2,400 – 3,000 babies born each year with a form of congenital heart disease. Cumulatively, taking into consideration newborns through to adults living with congenital heart disease, this number could conceivably represent well over 64,000 Australians.

Although there is no indication that the incidence of congenital heart disease is increasing, as Australian birth rates increase and enhanced medical care and technology continue to improve survival rates following medical interventions, the prevalence is predicted to increase. In particular, there are an increasing number of adults with congenital heart disease who are not well served by the existing health care system.

Gaining a better understanding of the entire spectrum of congenital and acquired heart disease, the number of people living with congenital/childhood heart disease, and the total burden of disease across the disease continuum is imperative to patients and those responsible for treating them.

Liddywoo age 14

Approximately half of the children diagnosed with heart disease require surgery to correct it.

Each week more than four Australians pass away as a result of a congenital/childhood heart disease.

Eight babies are born with a heart condition in Australia every day.

> Some children acquire heart disease - often as a result of rheumatic fever. which is prevalent in many communities.

THE FACTS

Congenital/childhood heart disease is the single biggest cause of infant mortality and death in children under the age of one in Australia greater than all the childhood cancers combined.

It is estimated that 32,000 children (under 18 years of age) are currently living with congenital/childhood heart disease in Australia.





On behalf of HeartKids we are pleased to release our inaugural HeartKids Annual Impact Report for 2016 - 2017. HeartKids Limited formally commenced on 31st October 2016 as a national charity and company bringing together staff and volunteers, programs and operations of the six previously State and Territory-based HeartKids organisations under one charity, one brand and one Board.

Since then, the HeartKids Limited Board has been working with the CEO on shaping the strategic directions of HeartKids and overseeing the implementation of a complex transition plan unifying the six organisations behind a single vision and common purpose.

The Board, in consultation with its Programs and Services; Health and Clinical Advisory; and Research Advisory Committees, has identified core advocacy, information, research and support priorities and has mapped a clear and positive way forward in the recently released 2017 to 2020 Strategic Plan.

The HeartKids Strategic Plan 2017 – 2020 maps a positive way forward for HeartKids and the congenital/childhood heart disease community more broadly. HeartKids understands that each family's journey is unique and our purpose is to help you navigate your congenital/childhood journey throughout your lifetime.

Our plan builds on the strength and success of the past 35 years by aligning an integrated model of care to support the eight babies born each day with congenital heart disease, the growing number of young people and young adults also living with and impacted by the disease, and those families that have lost a child or young person.

HeartKids will continue to strengthen our important work with families in hospital, supporting parents of newborn, infants and children when they are at their most vulnerable - at the point of diagnosis and during the numerous hospital stays in the first years of life. We will continue to support those experiencing financial hardships that need support and assistance to cope with the stress of caring for a sick child, including living away from home.

In this regard, our hospital work continues but with increased emphasis on evidence of impact, and where we can do the greatest amount of good. Our reach for families will grow to include more 'Parents as Mentors' in both hospital and in regional and rural remote communities.

Heart Angel families are also a critical part of HeartKids going forward with new resources and information, referrals to support, training for staff and the extension of financial assistance for grief and loss counselling for the family.

Looking forward, HeartKids seeks to broaden our services to young people in transition from paediatric to adult care, and young adults living with congenital/childhood heart disease. The evidence is very clear that these young people are at great risk of premature death and/or a less fulfilling life. The Board and paediatric and adult cardiologists who work with us strongly believe it is critical that our services are extended to support all people impacted by congenital/childhood heart disease throughout their life journey.

Mark Brooke Jan McClelland, AM Chairperson Chief Executive Officer

WELCOME FROM OUR CHAIRPERSON AND CEO



HeartKids Ambassador and heart kid parent The Hon. Steve Ciobo

INAUGURAL CONGENITAL/CHILDHOOD HEART DISEASE ROUNDTABLE SECURES HISTORIC NATIONAL ACTION PLAN

In September HeartKids facilitated the inaugural National Childhood Heart Disease Roundtable. The Hon. Greg Hunt MP, Minister for Health agreed to develop Australia's first ever joint Federal and State / Territory National Childhood Heart Disease Action Plan. This will see important recommendations from the 2011 CHD White Paper and newly identified gaps in services addressed in a comprehensive, integrated and evidence driven assessment of clinical and surgical care, for both children and adults impacted by congenital/childhood heart disease. Heart Kids Heart Kids Heart Kids Heart Kids Heart Kids Board Member Prof. David Celemajer AD



Minister Ciobo, Minister for Health The Hon, Greg Hunt, Jan McClelland AM and Mark Brooke HeartKids CEO

lvocacy • Information Research • Support



When it comes to our Advocacy work, HeartKids' key current priority areas are driven by continued consultation with people impacted by congenital/childhood heart disease. Our priorities include:

- Access to support funding
- Access to social, psychological and allied health support
- Bereavement support
- Transition from paediatric to adult care
- Travel for care

Access to support funding

HeartKids families and patients identified lack of access to funding and inconsistencies in access to supportive funding as a limitation of the current system. Consistently, families mentioned that parking at most of the hospitals was expensive and a substantial financial drain given the number of times they were required to visit hospitals. This and other matters have created a financial hardship for families. HeartKids is calling on the

We work with our health and hospital partners and supporters to ensure all Australians impacted by congenital heart disease and heart disease acquired in childhood, have a voice. HeartKids this year secured a commitment to government funding and support for Australia's first ever Childhood Heart Disease Action Plan.

ADVOCACY

government to ensure those affected by congenital and childhood heart disease and their families have access to the National Disability Insurance Scheme (NDIS) and if appropriate, Health Care Cards and Carers Benefits.

Access to social, psychological and allied health support

Given that it has only been relatively recently that the neurodevelopmental aspects of congenital/childhood heart disease have begun to be investigated in-depth, many families have been coping with brain injuries and psychological and psychosocial conditions with very little support. In many cases, one parent is not able to work, as the child with childhood heart disease required additional care. HeartKids Support Coordinators and family members consulted consistently identified the lack of support services as a major weakness of the current health system. In particular, the lack of access to social work services was noted.

Bereavement support for Heart Angel Families

Lack of bereavement support was identified in the 2011 White CHD Paper as a major area of focus. Bereavement support was seen to be particularly difficult for families living outside of the major metropolitan centres. When a family has lost a child, the family members rarely want to interact with families. HeartKids offers a limited Bereavement Support Program and provides financial assistance to Heart Angel families to access grief and loss counselling, increasing the take up rate of Mental Health Plans and the ease of access of these is a high priority for HeartKids.



A key pillar of HeartKids is providing evidence based, up-to-date and user-friendly information to families and adults impacted by congenital heart disease.

In total 254 people were referred to other services including mental health groups through the 1800 HeartKids Helpline. Those who used the service reported

> a high degree of satisfaction with both the information and the service itself.

Transition from paediatric to adult care

HeartKids has identified an urgent, emerging need to develop supporting health care systems and programs for young people transitioning from paediatric to adult care. There is a need for transition processes to assist young people to understand how to assume responsibility for their own health care, and ease the change to adult care. HeartKids families indicated that this was not done well currently, and they reported that many adults with congenital/childhood heart disease do not participate in appropriate medical follow up. It was also reported that there were limited options for these teens to access medical and life insurance, often leading to financial disadvantage. HeartKids is actively seeking Government support for a national teen transition strategy that puts in place age specific population health strategies that engage young people and support them on their journey into adulthood.

Tahlia-Jade age 12



Travel for care

HeartKids families from rural and remote communities report numerous examples of the difficulties associated with the need to travel for health services. The issues included: lack of sufficient funding to support travel (airfares, taxis, petrol etc.), need for financial support for child care for siblings, the cost of food while away from home, the lack of visitors when in hospital away from their community, the lack of access to affordable accommodation and inconvenience of travel when surgery is cancelled.

To this end, HeartKids is championing this issue with State and Federal Health Ministers to ensure funding is available to assist families, particularly those in rural and remote communities to access appropriate levels of assistance. We are also advocating that in the event of surgery being cancelled due to no fault of the patient, the full cost of travel and lost income should be fully reimbursed for all families impacted by congenital/ childhood heart disease.

The HeartKids Support Team at the Lady Cilento Children's Hospital in Brisbane are amazing. Our heart kid was born eight weeks ago and they have gone above and beyond with the support and everything else they do. It makes our time in hospital a little easier.

Carina Lindsay

INFORMATION

Information services strengthened and our reach to families grows

The HeartKids Helpline provides support, advice and guidance for anyone affected by congenital/childhood heart disease. HeartKids can assist with information about preparing for and taking care of yourself and your family during a hospital stay. For example, information is often requested on available accommodation, meals, transport and parking. We can also assist with information on the availability of certain hospital services such as social workers, occupational therapists, and speech pathologists.

Most valuable to our families during the crucial time of surgery are our HeartKids Support Coordinators. These coordinators are often 'heart mums' and understand more than most what families are experiencing during the often tension filled hospital stays.

Thanks to the generous support of donors in 2017–2018 HeartKids reshaped its information and advisory services; created a new centralised and up to date referrals directory to drive the 1800 HeartKids Helpline and revamped our website so that the information is current. With the aid of a donation from corporate partner Actelion, HeartKids was able to engage a professional medical writer to review and redraft our most commonly requested health fact sheets.



CONGENITAL HEART ALLIANCE OF AUSTRALIA AND NEW ZEALAND

AUSTRALIA AND NEW ZEALAND **CONGENITAL HEART DISEASE** REGISTRY

The largest research project ever facilitated by HeartKids

Founded in 2014, the purpose of CHAANZ (Congenital Heart Disease Alliance of Australia and New Zealand) is to facilitate research, aid with lobbying and build a continuum of community for people with congenital/childhood heart disease.

CHAANZ is a consortium of congenital heart disease researchers from across Australia and New Zealand established under the initiative of, and with funding from HeartKids. The CHAANZ team comprises paediatric and adult congenital/childhood heart disease cardiologists and the cardiac surgical teams they work with, as well as input from medical psychology. The Registry has been supported by HeartKids with financial assistance from The Kinghorn Foundation, The Pinnacle Charitable Foundation and other generous sponsors and donors.





RESEARCH

Leo Justin Ma

09.08.12

Unification has brought about a strategic

advantage for HeartKids in our research activities with increased investment, stronger collaborations with treating doctors and surgeons and the translation of evidence into program via the Family Coping Program.

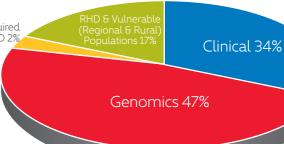
Aquired CHD 2%

RESEARCH **CELEBRATING 10 YEARS OF RESEARCH**

2016-2017 continues the strategic evolution of the HeartKids Research Program. The Program's two branches include the Grants in Aid program, and facilitation of the Congenital Heart Alliance Australia and New Zealand (CHAANZ) that has been brought together to implement a bi-national Congenital Heart Disease (CHD) Registry.

Our long-term aim is to define those areas of childhood heart disease research in which Australian researchers are recognised as a global leader, aligning these programs with corporate and community partners to ensure the quickest transition of research to treatment outcomes that benefit Australians impacted by childhood heart disease. As the total funds available to researchers from government is capped, HeartKids will work hard to continue to attract additional investment to meet the ever-increasing demand for funding.

Our contribution towards the advancement of scientific knowledge and improved treatments for Australians impacted by CHD is important and HeartKids encourages you to continue to support this important work.









In celebration of the 10th Anniversary of the HeartKids Research Program and the tremendous progress made towards greater understanding and improved treatment of congenital (childhood) heart disease (CHD), HeartKids is pleased to introduce its inaugural Roll of Honour Award.

This prestigious award recognises outstanding contribution to the field of CHD research both at a local an international level, with demonstrable impact on the treatment, management and/or prevention of CHD.

Recipient: Professor Yves d'Udekem MD PhD

Prof d'Udekem is an international leader in the field of paediatric cardiac surgery and is Deputy Director Cardiac Surgery Unit at the Royal Children's Hospital, Senior Research Fellow at the Murdoch Childrens Research Centre and Professor of Paediatrics at the University of Melbourne. His main research and clinical focus is the long-term outcome of patients born with a single ventricle who have undergone a Fontan operation. He is now leading the world's largest and most in-depth research of its kind in this patient population.

In 2011, Prof d'Udekem received project funding from the HeartKids Research Program to understand the complicated Fontan Physiology, and in 2012 received a HeartKids Grants-in-Aid to establish the first pilot Australian and New Zealand Fontan Registry. During this period, Prof d'Udekem collaborated significantly with other researchers in the field and received funding to measure the burden of untreated hypertension amongst patients with repaired aortic coarctation. Importantly, the initial funding of the pilot Fontan Registry led to Prof d'Udekem being successful in securing a \$1.25 million NHMRC Partnership Grant to improve the survival and quality of life of babies born with severe congenital heart conditions.

HeartKids is a partner with Prof d'Udekem in this NHMRC Partnership Grant, and it is these collaborations with Prof d'Udekem that have helped lead to the establishment of a pilot bi-national CHD registry project facilitated by HeartKids and supported by the Pinnacle Charitable Foundation (formerly Wilson HTM Foundation) and the Kinghorn Foundation.

Prof d'Udekem is very generous with his time and always makes himself available to the HeartKids and CHD community, speaking to the media, at educational events and providing support to patients and their families. He is a most deserving first inductee into the HeartKids Roll of Honour.

ROLL OF HONOUR AWARD



HeartKids funds research projects so that these funds can attract additional investment from government and others. In 2016 / 2017 HeartKids invested \$1M in congenital/ childhood heart disease research projects and multiplied this investment as researchers attracted an additional \$1.2M in funding.

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Freddie age 10 days

GRANTS-IN-AID AWARDS YOUR DONATIONS IN ACTION

PROJECT 1

ACE inhibitor cessation in the setting of well-functioning Fontan hearts

Principle Investigator: Professor Yves d'Udekem



Looking forward a strategic review of HeartKids Research Program will be conducted with extensive consultation with researchers to establish a progressive translational research agenda





PROJECT 2

Clinical and genetic studies in children with Left Ventricular Noncompaction Cardiomyopathy (LVNC)

Principle Investigator: Professor Chris Semsarian



PROJECT 4

Modelling CHD in a dish using IPS cells and massively parallel sequencing

Principle Investigator: Richard P. Harvey, PhD FAA FAHMS FRS



PROJECT 6

Nitric Oxide to reduce cardiopulmonary by passinduced inflammation after cardiac surgery in children

Principle Investigator: A/Prof Luregn Schlapbach, FCICM



PROJECT 3

- Mechanisms and predictors of cardiovascular risk in children following Kawasaki disease
- **Principle Investigator:** Professor David Burgner



PROJECT 5

- Burden of rheumatic heart disease: comprehensive measurement to drive the Endgame
- Principle Investigator:
- A/Prof Judith Katzenellenbogen



- PROJECT 7 Early detection of hypertension in aortic coarctation using genome sequencing
- **Principle Investigator:** Professor Fadi Joseph Charchar







Hospital support for families

HeartKids employs over twenty staff located in Children's Hospitals in Adelaide, Brisbane, Canberra, Darwin, Melbourne, Perth and Sydney. We work in partnership with Hospitals as visiting non-government organisations.

HeartKids Regional Support Coordinators (both paid and volunteer) also work in a number of regional and rural communities to support people living with congenital/childhood heart disease and their families particularly returning from hospital as outpatients.

We became members of HeartKids
22 years ago. Our heart kid went to heaven at 4 years old, post cardiac surgery.
We still have ongoing friendships that we made all those years ago with now young adults, older teens and their beautiful families.

> Margaret Faulkner Heart Angel Parent

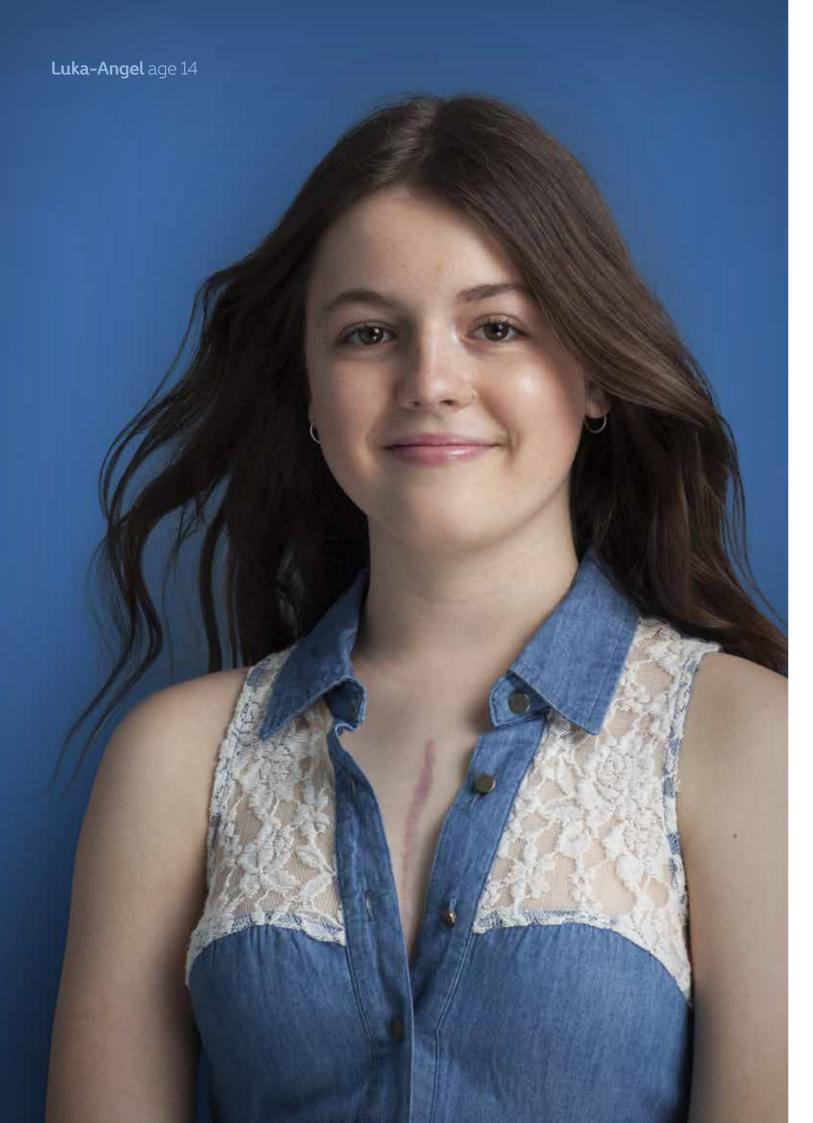
SUPPORT HEARTKIDS SUPPORT TEAM STRIVE FOR EXCELLENCE

At the heart of our Support Program is the Support Team, a passionate and dedicated group of Social Workers, Nurses and allied health professionals, many of whom are heart kid parents themselves. Our team is assisted by a number of trained HeartKids Volunteers who also provide assistance to families and act as buddies, mentors and supporters. The role of our Support Managers and Coordinators is to assist and support patients and families with information about their hospital stay, for example information on available accommodation, meals, transport and parking and link with or introduce your family to hospital services such as Social Workers, Occupational Therapists, and Speech Pathologists. As well as offering support to people living with congenital/childhood heart disease and their families, HeartKids also acts as a compass to guide them on their journey as and when they need support. Support is available to any person living with or diagnosed with congenital or acquired heart disease regardless of age as HeartKids supports heart kids through life.

HeartKids holds regular morning teas and events in hospital and in the community to connect families, young people and adults.

These morning teas and events are a great chance to meet other families and hear first-hand about their experiences. They are rated very highly by families given the shared experience.





Teen Transition Workers

In NSW/ACT and VIC/TAS HeartKids employs specialist part-time Teen Transition Workers whose role is to assist young people aged 13 to 25 living with congenital/ childhood heart disease. These workers are specialists in teen transition and assist young people and young adults and their families in moving from children's hospital to adult hospitals and care.





YOUNG PEOPLE

Teen Camp

Teen Camp 2017 was held on Rottnest Island, off Perth, West Australia and brought together 70 heart teens between the ages of 13 and 17 years.

The camp is an inspiring and unique opportunity for heart teens to connect with others who may have experienced a similar journey, develop new friendships and create ongoing peer support networks.

Importantly, Teen Camp gives heart teens the chance to attempt physical and team building activities in a supportive and safe environment where peers understand each other's limitations.

Young people who attended the Camp reported decreased feelings of isolation and being alone, many observed increased resilience and confidence and increased feelings of self-esteem and worth.

The camp is not simply a recreational opportunity but importantly provides participants an opportunity to test their individual capacity in a safe





environment as a number of these young people are restricted in their participation in school and community based activities.

HeartKids would like to acknowledge the tremendous support and generosity of our supporters and the camp nurses, doctors, volunteers and other staff who donate their time and expertise. Teen Camp relies on funds raised from the community and the corporate sector.



HeartKids Heart Bead program
 was started to give children like mine
 the opportunity to share their childhood
 heart disease journey every bead is a reminder of
 how lucky we are.

Sarah Mum to Cody

FINANCIAL ASSISTANCE PROGRAM

Fast facts

In 2016–2017 HeartKids provided direct financial relief to 196 heart kid and Heart Angel families Australia wide. 65% of these families resided in rural and remote communities and 80% travelled intra or interstate for surgery. The shortest time away from home was 2 days, the longest 272 days (ongoing). Total financial support for the year was \$235,914 - \$65,000 more than last year

Dylan age 4 months

HeartKids understands that congenital/childhood heart disease significantly impacts patients and their families especially when a baby, child or teen is hospitalised and families need to travel intra and interstate for surgery. HeartKids families' lives can be turned upside down as parents care for their babies and children whilst juggling siblings, work and running a household.

One or more parents may be forced to use up their leave or give up work entirely. For some with the help of family and friends many navigate their journey, however childhood heart disease causes significant emotional, physical, financial anguish and worry. Thanks to our donors and corporate partners, HeartKids offers a Financial Assistance Program for families and/or caregivers of children and young people diagnosed with and undergoing treatment for congenital/childhood heart disease. Depending on the local arrangements assistance is provided to families for accommodation, travel and meals and directly supports vulnerable families in particular those in rural and remote communities. Heart Angels are precious and HeartKids acknowledges the distress and anguish caused by the death of a child to entire families.

To support families at this difficult time HeartKids provides:

- Financial assistance towards the cost of a Heart Angel's funeral
- Financial assistance for grief and loss counselling to support parents and or siblings
- In memorial jewellery to remember your child.



FAMILY COPING PROGRAM PILOT

The HeartKids Family Coping Program was developed support team over two weekends. by the Australian Centre for Heart Health and Melbourne Piloting of the HeartKids Family Coping Program was University following funding by HeartKids Grants-In-Aid. undertaken with two five-week sessions covering: program

HeartKids researchers believed that the presence of a chronic condition like congenital/childhood heart disease in children may place the wellbeing of the whole family at risk. They conducted in-depth interviews with participants recruited through HeartKids to explore parent/carer's experience of parenting a child with congenital/childhood heart disease. After analysing the data the researchers recommended a new program of family intervention to target adaptive coping and productive parenting and the findings were used to adapt the 'Parents Can Do Coping' program for parents/carers of children with congenital/childhood heart disease.

In February 2017 the research team conducted a training



Yves age 6 months

session for the HeartKids Victoria/Tasmania division

- The positive psychology of parenting: supporting health and wellbeing
- Adjusting to a family life with chronic conditions
- Strengthening family's coping strategies
- Helping your child to express feelings in the early years
- Tuning in to siblings
- Using assertiveness to advocate for yourself and your child
- Empowering your child to cope
- Partners working together towards improving their relationship
- Adjusting, accepting and healing through Mindfulness
- Helping your child through transitions

The new program was extended to regional communities to further test the model.

The training is co-facilitated by Associate Professor Rosemary Higgins

The HeartKids Family Coping Program fills an important need for our community providing a holistic approach to early psychosocial intervention targeting improved adaptive coping and enhanced productive parenting practices. Research has shown the positive impact of parenting programs on parental mental health, parenting practices, communication and problem solving.

The Program delivery and review shows a commitment to evidence informed practice and HeartKids is delighted to expand this program nationally in 2017 / 2018.



HEARTKIDS CARE BAGS

HeartKids Care Bags play a strategic role in increasing the reach of our in-hospital support services. These bags are an introduction to the work of HeartKids and open the door to a range of additional

congenital/childhood heart disease and the HeartKids Care Bag offers a form of support that can come Our amazing HeartKids Support Team provides HeartKids Care Bags to our families in hospital or to families travelling regionally for their child's life saving heart surgery. Participating hospitals nationally are Westmead and Randwick Children's Hospital, Princess Margaret Hospital, Royal Children's Hospital

With the support of Amway, these red cotton tote bags are HeartKids branded and they contain laundry liquid, shower cap, grooming kit, snack items, useful information and a notebook and pen.

Proudly supported by



The growth and impact of Sweetheart Day 2017 was demonstrated by achievement of 15 million media impressions, Facebook post reach of 2.6 million and a 47% increase in funds raised campared to the 2016 campaign.







IN THE COMMUNITY

HeartKids promotes and advances awareness of congenital/childhood heart disease through a number of community awareness campaigns. Three national campaigns were delivered in 2016–2017 to ensure all Australians understand the burden of disease and the impact on all people living with or impacted by congenital/childhood heart disease.

HeartKids Sweetheart Day 2017

The unification of HeartKids and the maturity of the new organisation was perhaps best demonstrated in our community coming together to build awareness of

> congenital/childhood heart disease in the broader community. Sweetheart Day, also known as Valentine's Day, is International Congenital Heart Disease Day and Heart-Kids' largest campaign.

The campaign resulted in over 25 million media impressions and a very large surge in social media activity. With thanks to our staff and volunteers, Sweetheart Day greatly improved the community's understanding of childhood heart disease and its impact on families.

With thanks to Virgin Money, our Sweetheart Day partner who matched donations up to \$50,000, a surge in

donations resulted in a record \$375,000 (almost double the year prior) being raised for HeartKids in-hospital support program.







HeartKids Two Feet & A Heartbeat Charity Walk

In recognition of the fact that the human heart begins to beat 21 days after conception, HeartKids Two Feet & A Heartbeat is a 2.1km walk, allowing participants to take positive steps towards finding a cure for congenital/ childhood heart disease, whilst enjoying the mental and physical benefits of moderate exercise.

Participants walk side by side with HeartKids families learning more about their journey and their challenges. Each participant carries a coloured flag creating a powerful visual effect.

Blue is carried by those with congenital/childhood heart disease, red by those walking in support and white by those walking in memory of a Heart Angel.

The 2016 walk concluded with a twenty one second silence in memory of our Heart Angels.

This is an emotional time of reflection as families commemorate the lives of infants and children who have died. HeartKids annual charity walk unites us and offers a true sense of community.

For the first time walks took place in each major capital city and many local communities across the country. Over \$180,000 was raised and will be invested into HeartKids' programs.

02 9460 7450 • office@heartkids.org.au • heartkids.org.au



HeartKids Super Boss Day

May 26 was Super Boss Day, HeartKids national day of action for corporate leaders and business owners to raise funds for life saving childhood heart disease research.



This year 228 Super Bosses from every corner of Australia participated raising \$353,000 - a new record for HeartKids (\$130,000 more than last year). Now in its third year Super Boss Day is proving an effective and fun corporate engagement fundraising campaign that captures the attention of employers and employees alike.

HeartKids would like to acknowledge and thank the tens of thousands of heart kid parents and supporters who sponsored and donated to their favourite Super Boss.

"People's Choice Credit Unit was proud to partner with HeartKids for Super Boss Day. Our Senior Leadership Team



people's choice credit union

It's a great opportunity to have a bit of fun with our staff and raise money while we're at it. Who hasn't dreamed of being a superhero for a day?"

Mark Hodgson

CSR & Sponsorship Coordinator People's Choice Credit Union



SOPHIE'S STORY

The sound of little Sophie Adeline's laugh is music to the ears of her parents, Sam and Ben Adeline. Sophie, who turned one on 17 February 2017 didn't laugh or cry for six months after a series of lifesaving heart operations resulted in paralysis of both of her vocal chords. Sam and Ben feared the paralysis was permanent but Sophie has finally started to make some noise.

"She is still really quiet and her cry is not very loud. People comment a lot that they have never seen such a quiet baby," Sam says.

To hear Sophie laugh and cry, to say Mummy and Daddy, is a high point in a heart wrenching rollercoaster ride that started when Sam was 20 weeks pregnant and a routine scan revealed her little girl had a congenital heart disease.



Sophie age 1 year

The two main arteries going out of her heart were transposed and the wall separating her heart ventricles had two holes. "When we went in for the ultrasound we thought we were going to see if we were having a boy or a girl, CHD wasn't on our radar, we were completely blindsided," Sam says. Sophie had surgery on the day she was born to allow her blood to mix and in her first week she also had full openheart surgery. She was due to come home three weeks later but final checks revealed a bacterial growth on a heart valve that required a six-week course of antibiotics, administered straight to her heart.

Sophie was nine weeks old before Sam and Ben were able to take her home and she had already grown out of the clothes in the top two drawers of her wardrobe.

Sam, a mum of two who has a history of pulmonary embolism that put her at a high risk of blood clotsclots during the pregnancy and after Sophie was born, said she was shocked by the lack of awareness about CHD that is the biggest killer of our babies.

Eight babies a day are born with CHD in Australia and each week four people die from the condition.

For Sam, HeartKids was a lifeline. "When everything first happened, no-one knew what we were going through. We felt like we were the only people this was happening to, we didn't know what to, we didn't even know what to Google. To go from that feeling, of being so alone, to getting on Google and finding HeartKids and meeting other CHD families made all the difference - all of a sudden we were not alone anymore." HeartKids is extremely grateful for the commitment and support we receive from individual heart kid and Heart Angel families, members of the community as well as philanthropic trusts and foundations, corporate partners and government. HeartKids is 99.96% community funded and receives no government funding. Thank you to all who are helping infants, children, young people and adults navigate their childhood heart disease journey.

PRINCIPAL PARTNERS



Major Gifts (\$10K+)

Bailey and Lisa Garcha John Ribot Anita Wagg

Trusts & Foundations (\$10K+)

Perpetual Limited – Hecht Family Trust Graf Family Foundation The James and Jutta Lauf Foundation Sheargold Family Foundation Pty Ltd The Coca Cola Australia Foundation The QBE Foundation Lotterywest Younis & Co Foundation Commonwealth Bank of Australia – Staff Community Fund St George Foundation Gambling Community Benefit Fund (Queensland)) eBay / Silicon Valley Community Foundation

SUPPORTERS AND ACKNOWLEDGEMENTS

Research and Corporate Partners (\$20K+)

Actelion Admedus Biggin & Scott Kennards Group Grove Hire Jett Couriers Concert ICT The Good Guys Edwards Life Sciences Titanium Services Group JMC Group Kiwanis Charitable Foundation

Community Supporters (\$10K+)

National Variety - the Children's Charity

New South Wales / Australian Capital Territory

Northern Beaches Social Riders 'Team Charlie' – The Canberra Times Fund Run – Audi Club Sydney

South Australia / Northern Territory

Cops for Kids – South Australia Tour De Lyndock 2017 – South Australia Football Federation South Australia – South Australia Tour de Francis (Glastonbury Family)

Queensland

Rotary Club of Ipswich City Carter's Cause Sparkling Hearts Soiree – Karen and Greg Millican Heart and Soul Gala Ball – Amanda and Corey Schmidt Biennial Charity Luncheon - Toowoomba North Queensland Hope For Hearts Gala Ball – Townsville Former Origin Greats (FOGS) HeartKids Hero Noosa Tri Team 2016

Victoria/Tasmania

- Broadmeadows Car & Bike Show
- Final Field Cox Plate Luncheon
- Makayla Cook Golf Day
- Simple Pleasures Brunch
- Sharpies Charity Challenge

West Australia

HBF Run for a Reason 2017



GOVERNANCE

HeartKids governance and ethical leadership

As a charitable institution and Company Limited by Guarantee, HeartKids Limited is reliant upon community and corporate goodwill to achieve its goals.

As a community organisation, HeartKids also has considerable legislative, administrative and other accountabilities as required by the Australian Charities and Not for profit Commission (ACNC) that need to be maintained to a high standard.

The Board is comprised of twelve Directors who bring expertise in congenital and acquired heart disease medicine, medical science and research, governance and executive management, finance, law, marketing and communications, not-for-profit administration, as well as extensive networks within the corporate, public and government sectors and the broader community.

Emeche age 21 years

Role of the Board of Directors

The role of the Board is defined by the HeartKids Limited The Board adopted its inaugural three-year Strategic Plan Constitution, which is the legal instrument guiding the in May 2017 following the unification of the five existing organisation. All Board members, staff and volunteer operate State and Territory organisations. This outlines our Mission, in line with a Code of Conduct – Every Day Every Way. Purpose, Values, Goals and Strategies. These strategies are The Board's role is to ensure a range of strategies that outcome-focused and are measured by clearly defined key support people impacted by congenital/childhood heart performance indicators (KPIs). disease is achieved. Our Strategic Plan includes:

To undertake this role, the Board is responsible for the overall corporate governance of the organisation. This includes:

- Formulating its strategic direction;
- Approving and monitoring financial performance;
- Setting executive remuneration;
- Appointing, removing and creating policies;
- Establishing and monitoring the achievement of organisational goals; and
- Ensuring the integrity of internal control and management information systems.

The Board is also responsible for approving and monitoring finance and other reporting and compliance.

The Board delegates responsibility for the operation and administration of the organisation to the Chief Executive Officer. Responsibilities are delineated by formal authority delegations.

Board processes

To assist in the execution of its responsibilities the Board of Directors has established a number of committees including:

- Finance, Audit and Risk Sub Committee;
- Research Advisory Committee;
- Program and Services Sub Committee;
- Development Advisory Committee;
- Health and Clinical Advisory Sub Committee; and
- Congenital Heart Alliance of Australia and New Zealand (CHAANZ) Sub Committee.

These committees have written terms of reference and operating procedures reviewed on an annual basis.

OUR BOARD MEMBERS

Board planning framework

- A national plan, incorporating five-year performance targets;
- An annual business plan and budget relating to the strategic plan;
- A reporting framework against KPIs;
- Delegated authorities, recorded in a policy framework, from the Board to the CEO and staff, built around a performance culture measured by a performance appraisal process;
- A risk management plan; and
- A quality assurance framework supported by a program logic and policy manuals.

Board of Directors education

HeartKids has a formal process to induct and educate new and continuing Directors about the nature of the organisation, health and medical issues, the corporate strategy and the expectations concerning performance and conduct of Board Members.

Role of the Board of Directors

The Board is a skills based Board and is broadly representative of the congenital/childhood heart disease community. It includes Cardiologists, health sector professionals and policy analysts, medical researchers, parents of children with congenital heart disease and adults living with congenital or acquired heart disease. Fifty percent of the Board is female and seventy percent have direct or lived experience of congenital heart disease either as a patient, family member, or treating health professional. Board sub-committees also represent a diverse community, including Heart Angel families.

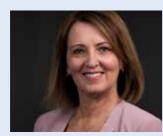
MEET OUR BOARD



Ms Jan McClelland AM Chairperson

Jan McClelland AM is a company director with more than 12 years' governance experience as chair and non-executive director in government, of industry sectors including the commercial, industry association and private sector, she is currently a not for profit enterprises across a range of industry sectors.

Jan is a former Director-General of the NSW Department of Education and Training and Managing Director of TAFE NSW. She is currently Deputy Chancellor and Council Member of the University of New England, Chair of the superannuation industry's Gateway Network Governance Body, a Director of UNE Partnerships and a Director of Stewart House Preventorium.



Ms Bev Barber Director

Bev Barber is an experienced Executive and Non-Executive Director with a background spanning a range Director with PwC and throughout her career has worked across State. Federal and Local Governments.

Bev has worked with ASX listed companies and small to medium enterprises and was a Board member on the HeartKids Australia Board and more recently also on the South Australian Board.



Ms Jayne Blake Director

Jayne has been a Director of HeartKids since 2011, previously in the roles of Chair of HeartKids Australia, Chair HeartKids New South Wales and has also been Chair of the Audit, Risk and Compliance Committee and Chair of the Alignment and Engagement Committee of HeartKids Australia.

Jayne is an experienced company director with broad cross-functional expertise including key Executive roles in Finance, Sales, Commercial and Customer Relations. In her corporate career Jayne worked for Vodafone Group in various General Manager roles in both the UK and Australia, in Finance, Commercial and Customer Service functions, until becoming Sales Director in 2004. Bringing all this experience together Jayne established JBC International, a coaching and consulting business in 2009, specialising in assisting other organisations to effectively plan for and drive sustainable business growth.



Mr Jared Brotherston Director

Jared has over 15 years' experience as a director and company secretary in both Australia and New Zealand. He has been a construction barrister. and held company secretarial and general management roles in postal services, construction and transport and logistics. He is a former Associate and Clinical Director at The Heart Director in KPMG's Major Projects team and consulted to the oil and gas and resources sector.

More recently, Jared held a senior commercial role as Manager Contracts and Procurement for the Roy Hill mining project based in Perth. Currently, he is Head of Operations for Australian Academy of Science since a consulting company specialising in supply chain optimisation.



Prof. David Celermajer AO Director

David Celermajer is the Scandrett Professor of Cardiology at The University of Sydney, Director of Echocardiography in the Cardiology Department as well as Director of Adult Congenital Heart Services at the Royal Prince Alfred Hospital Research Institute.

Some of David's major achievements include; NSW Health Minister's Award for Lifetime Achievement in Cardiovascular Research in 2012, Simon Dack Award for excellence in cardiology in 2010, Fellow of the 2006 and Commonwealth Health Minister's Award for Excellence in Health and Medical Research, for outstanding lifetime contribution in 2002.





Mr Rohan Geddes Director

Rohan has over 25 years' experience in personal and employment related tax matters, specialising in FBT, payroll tax, superannuation, employment termination and redundancy arrangements and PAYG.

He is a Partner at

PricewaterhouseCoopers, where he leads the Employment Taxes and Payroll Consulting Practices. In these roles, he provides proactive advice to employers, assisting them with the processes and policies used to help manage the tax and administrative impacts of remunerating their employees and their contractors. He has also worked in Australia and the US, providing personal tax assistance to high net wealth individuals and expatriates. Rohan is a heart kid.



Ms Sami Glastonbury Director

Samantha Glastonbury is a Sales and Marketing professional with 15 years' experience in the wine industry nationally and internationally. Sami is law. He is currently responsible for also heart mum to 3-year-old Francis who was born with a congenital heart defect. Sami and her husband are very active in fundraising and raising awareness for HeartKids and have collectively fundraised close to \$75k in the last 2.5 years

Sami has volunteered her time in her local non-profit community for the past 6 years. Firstly with the local community childcare and successfully help make it compliant to government and legislation standards, then in January started as a non-director on the board of HeartKids SA/NT.



Mr Anthony Mahady Director

Anthony is an experienced lawyer, having practised in both Australia and of a boutique not for profit practice the UK, primarily in financial services managing the prudential regulatory risk of a major Australian financial institution. In addition to his legal qualifications Anthony also holds a Master of Applied Finance.

Anthony has three young children, heart condition. Anthony is also a member of the Programs and Services Advisory Committee.



Dr Joanne Redburn Director

Dr Joanne Redburn is the principal bringing years of experience in corporate, commercial and intellectual property law, to the not for profit sector.

Because of the highly focused nature, Joanne has developed a specialised knowledge of the sector, working with a diverse range of not for profit one of which suffers from a congenital and social enterprise clients. She not only understands the legal needs of the sector but also understand what motivates the sector. Joanne is the parent of an adult heart kid.



Prof.Ruth Salom AM Director

Professor Ruth Salom is a medical graduate, specialist pathologist, with more than 30 years' experience in health, medical education, research and health management.

Ruth is currently Professor / Director of Pathology at Monash University. Ruth is a former Non-Executive Director of Melbourne Health and Peninsula Health as well as former Director National Health KPMG. Executive Director of SA Pathology and Head of Integrated Solutions at Telstra Health.

Ruth holds a Bachelor of Medicine Bachelor of Surgery from Monash University, Bachelor of Medical Science from Monash University, Doctor of Medicine from Monash University, Master of Business Administration from Melbourne University, Fellowship from the Royal College of Pathologists Australasia and is a Fellow of the Australian Institute of Company Directors.



Dr Lisa Selbie Director

Dr. Selbie received her Ph.D. in Molecular and Cell Biology from Northwestern University and has experience in cardiovascular research, project management, consulting and teaching.

Dr Selbie held research positions at the Garvan Institute of Medical Research and Queens Medical Centre, Nottingham as a Wellcome Trust Research Fellow studying cardiac neuropeptide receptors, and was involved in consultancy reviews of national research funding processes. Dr Selbie is a lecturer with Johns Hopkins University MS/MBA Biotechnology Program developing and delivering on-ground and online courses, serves on the NSW AusBiotech Committee, and previously was Chair of HeartKids Australia and the Research Advisory Committee.





Mr Matthew Tognini Director

Matthew has a passion for helping businesses achieve their potential. Throughout his career as a chartered accountant he has worked closely with his clients to help them not only achieve financial independence but to also help them to optimise their business structures and operations.

In his business career Matthew has worked and specialised in SME business clients. He has overseen taxation compliance, strategic planning, restructuring and human resources issues for a variety of clients. Matthew came to HeartKids through the diagnosis of his daughter, before birth, with a complex congenital heart defect.

OUR PEOPLE

In 2017, HeartKids Limited conducted our first staff engagement survey with the Voice Project. The survey was undertaken to create a baseline measure of engagement and work practices following the merger from separate state-based organisations into a national organisation in 2016. HeartKids has an ambition to be regarded as an Employer of Choice.

The survey provided staff with the opportunity to give confidential and de-identified feedback about the quality of current work practices at HeartKids, and to provide feedback on the impact and challenges of the merger. The survey also enabled the two outcomes of Passion (employee engagement) and organisational Progress to be measured.

The key findings from the survey data and recommendations about actions that can be taken to maximise passion and organisation progress have been converted into a national and divisional workforce plan. HeartKids performed very well when comparing our performance against an industry benchmark of sixty-two other Health Promotion and Health Advocacy Services organisations.

The HeartKids Staff Survey achieved an excellent participation rate, with 96% of staff completing the survey.

Overall, the results indicate that staff have high levels of passion/employee engagement (87%) and this result is 13% higher than the Health Promotion and Health Advocacy Services benchmark average.

rganisational commitment and job satisfaction are high, particularly in relation to staff willingness to put in the extra effort for HeartKids (100%) and staff enjoying the type of work they do (98%).

High performing human resources practices

Staff told us that HeartKids has key strengths in 'Purpose' related practices: particularly in staff alignment with mission and values (96%), awareness of organisation direction and strategy (90%), results focus (87%), and role clarity (86%).

Our team also expressed a high level of satisfaction with 'People' related practices in relation to teamwork (88%), and motivation and initiative and talent of their immediate co-workers (83% respectively). Of these, HeartKids significantly outperformed the benchmark average in relation to organisation direction (+23%), mission and values (+10%), motivation and initiative (+10%), and talent (+6%). Staff also indicated higher than average satisfaction with the senior leadership team (+6%).

Focus Areas

Technology (22%), resources (44%), career opportunities (22%), and learning and development (31%) are focus areas for HeartKids.

Workforce goals for 2017-2018

• Measuring performance against standard KPIs and quantitative and qualitative targets for all staff to improve clarity of roles and responsibilities and increase accountability;

• Complete phase one of the HeartKids Information Technology Infrastructure project recently funded by Perpetual Trustees. A recently acquired \$100,000 grant will allow all staff to work on a common platform and introduce shared files for the first time. In addition, the grant has allowed for 90% of computer hardware to be replaced with new commercial grade notebooks and desktop computers.

• Increasing cross team collaboration by using both technology (video teleconferencing team meetings) and a new intranet are also to be implemented to improve cross team collaboration and information sharing.

• Finally, a Workforce Development Plan is currently being prepared to identify skills gaps and areas of professional and personal development and provide staff and volunteers with skills, training and education to better equip them to serve our organisation.

• Following a restructure of HeartKids administration and finance functions significant duplication was noted and accordingly a decision to improve productivity and efficiency was taken resulting in the redundancy of nine staff nationally. These savings were redirected towards programs and services. HeartKids provided career advice and support through an external outplacement company who were engaged to work with staff to place them in new employment.



FINANCIALS AT A GLANCE

HeartKids Limited full Financial Statements for the year ended 30 June 2017 are available for downloading at heartKids.org.au. The amounts cited in this Impact Report specifically referring to service delivery combines HeartKids Limited and the former State HeartKids organisations. Please note the transition of financial controls, revenue, investments and expenditure etc from the former State HeartKids organisations was conducted over several months in a carefully planned transition and therefore this financial summary reflects this. Should you require more details or have any questions please contact accounts@heartKids.org.au and we will be delighted to assist you.

Statement of Financial Position

As at 30 June 2017

ASSETS	2017 \$
CURRENT ASSETS	Ť
Cash and cash equivalents	2,455,206
Trade and other receivables	158,999
TOTAL CURRENT ASSETS	2,614,205
NON-CURRENT ASSETS	
Property, plant and equipment	11,341
Intangible assets	25494
TOTAL NON-CURRENT ASSETS	38,835
TOTAL ASSETS	2,651,040
LIABILITIES	
CURRENT LIABILITIES	
Trade and other payables	332,109
Employee benefits	153,145
Deferred income	1,583,938
TOTAL CURRENT LIABILITIES	2,069,192
NON-CURRENT LIABILITIES	
Employee benefits	29,161
TOTAL NON-CURRENT LIABILITIES	29,161
TOTAL LIABILITIES	2,098,353
NET ASSETS	552,687
EQUITY	
Retained earnings	552,687
TOTAL EQUITY	552,687

Statement of Profit or Loss and Other Comprehensive Income As at 30 June 2017

Revenue earned
Transfer from State Branches
Other income
Fundraising expenses
Program, research, grants and support expenses
Salary and wages
Finance and administration
Other expenses
Income tax expense
Income tax expense
Surplus from continuing operations
Surplus for the period
Total comprehensive income for the period

2017
\$
2,054,626
1,954,142
62,434
(455,337)
(664,816)
(1,918,175)
(73,662)
(406,525)
552,687
-
552,687
552,687
552,687



HOW YOU CAN SUPPORT US

Help us fight congenital/childhood heart disease. There are many ways that you can be part of the solution. HeartKids receives no government funding and relies solely on the generosity of the general public to continue funding vital medical research as well as life-changing in-hospital support. Your support, no matter how big or small, will go towards supporting kids with congenital/ childhood heart disease, the single biggest killer of Aussie kids under the age of one. Donate

donation and directly support our life saving work

> Beguest Leave a gift in your will to create a

Volunteer

Make an impact by donating your time

Partner

Become a corporate

Participate

Attend an event or hos your own to support HeartKids

 Our beautiful daughter Coco Grace was born at Westmead Children's Hospital on 24th May. She has Hypoplastic Left Heart Syndrome and Truncus Arteriosus

 our journey has not been easy. My wife and I want to make special mention to HeartKids who reached out to us and many other families here at Westmead.
 I want you to know we appreciate your HeartKids team at Westmead and we would be lost without them! You all do an amazing job and we hope to get on board and raise awareness once we are in a position to do so!!

> Brad Dad to heart kid Coco

For more information or to make a gift today please visit heartkids.org.au or free call 1800 432 785.

All donations over \$2 are tax deductible.

If you would like to hear about our projects or funding opportunities please contact Shalani Dennis, National Fundraising Manager, on 02 9460 7450.

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