

A young child with dark hair and large eyes is lying down, looking towards the camera. They have a nasal cannula taped to their face and several ECG electrodes on their chest. A colorful toy rattle is visible in the bottom left corner. The background is a soft, white, textured surface.

ANNUAL IMPACT REPORT 2019



Supporting heart kids through life

THANKYOU

CORPORATE PARTNERS

The Kinghorn Foundation



SUPPORTING PARTNERS



GOVERNMENT SUPPORT

Australian Government's Department of Health
The West Australian Government's Department of Health

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MAJOR SUPPOTERS AND GIFTS IN MEMORY (\$5,000+)

NSW | ACT

Amanda Kercher-Hack
Bunnings NSW
HeartKids Hillclimb
Jayne Blake
Jodie Heterick
Northern Beaches Social Riders Club – national partner of the Heart Beads Program
Rohan Geddes
The Much Loved Yuna Ko
Virgin Money Australia – Aspire for change

WA

Adam Malaspina
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MarketPlace Fresh
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QLD
Ange Christofis
Beck Carter
Btuned Euro Specialist
Carter's Cause
Catie Eccleston
Gia Grace Helping Heart Luncheon
Isabella Storer
QLD Hellenic Charitable trust
Rotary Club of Ipswich City
Team Joshua - Elaine McGivern, Tara Peacock, Barry McGuire and William Mitchell

SA | NT

Kate McGregor
Hassan Alwan
Mine Tech Engineering
Timms Real Estate
Will McGregor

MEDIA PARTNERS

GT Media
Initiative Media
Lightbulb Design
WriteAway
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HEARTKIDS MISSION

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

Our free of charge support is a commitment for life because there is no known cure.

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

Vision Statement

Supporting heart kids through life.

Purpose

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

Our Values

- Care
- Collaborate
- Lead
- Perform
- Think

Guiding Principles

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



Lakyn Age 5

On behalf of the Board of Directors and staff of HeartKids Limited (HeartKids), we are pleased to present HeartKids' Impact Report for the year ending 30 June 2019.

HeartKids has a proud history and proven track record of more than 40 years of delivering programs and services to help children, young adults and adults living with congenital (or acquired during childhood) heart disease (CHD) lead the most fulfilling life possible and reach their personal goals. Our core purpose 40 years ago, supporting heart kids and those impacted by CHD, remains central to our work today, and provides a focal point for our programs and services in advocacy, information, research and support.

Supporting HeartKids through life

This report summarises our third year of operation as a consolidated national entity providing lifelong support for 65,000+ Australian babies, children, teens and adults affected by CHD, and their families and carers.

During 2018/2019 HeartKids worked closely with heart kids, parents of heart kids and heart angels, researchers, clinicians, health professionals, government policy makers and community representatives to develop Australia's first national action plan for CHD. *The National Strategic Action Plan for Childhood Heart Disease – Beyond the Heart: Transforming Care* (the Action Plan) was launched in Canberra in February 2019 by the Australian Minister for Health, the Hon Greg Hunt MP, together with a commitment to support research into congenital heart disease and implementation of the Action Plan. The Action Plan presents a comprehensive overview of the Australian CHD landscape, identifies needs, emerging challenges and opportunities for the CHD community and makes important recommendations in relation to identified priority areas for action. These include:

- development of Australian standards and models of care for CHD;
- planning for workforce and infrastructure requirements;
- tackling neurological and mental health issues;
- progressing research priorities;
- enhancing CHD awareness and education among clinicians and health professionals;

- improving access to information, education and services for CHD consumers including those in remote and rural locations and priority populations; and
- monitoring and reporting on the implementation of the Action Plan recommendations to ensure tangible benefit for those impacted by CHD and the wider community.

In January 2019 HeartKids welcomed Rob Lutter as the CEO of HeartKids. Rob is the former CEO of Heart Kids New Zealand and a father of a heart kid. He brings to the role a deep passion for providing support and services for heart kids and their families along with extensive experience in business and the not-for-profit sector, including delivery of programs and services, fundraising and advocacy.

Throughout 2018/2019 our dedicated team of state managers and staff across Australia have continued to provide direct support to HeartKids and their families in hospital, after discharge, and when back in their own communities. In 2018/2019, we assisted 7,300 people living with or impacted by CHD across Australia, including coordinating peer support for families whose children have similar conditions, coordinating family networking activities and providing practical support and assistance to families in need.

Our Teen Camp, held in Queensland in July 2018, provided an opportunity for teenagers and young adults with CHD from across Australia to come together to develop their communication and leadership skills in a safe and stimulating environment and to develop lifelong support networks to assist them in their transition from paediatric to adult care.

During 2018/2019 we have continued to raise awareness of CHD through education days, publications and information services, and we have continued to invest in CHD research through the Grants in Aid Program and the development of the Fontan and CHANZ database registries.

This report highlights only a small part of a significant amount of work completed by our very dedicated team of staff, board directors, volunteers and supporters this year. While we have achieved a lot, including Federal Government recognition of CHD as a national health priority and delivery of much needed services to families in need, there is still much to be done to address the unmet demand for programs and services.

On behalf of the HeartKids Board, we extend our sincerest thanks to all those who have contributed their time and resources to support our organisation and help us achieve our goals this year and the years to come.

Building on the strong foundations established in the development of the Action Plan, the close partnerships we have established with clinicians, researchers, government and consumers and our significant achievements in advocacy, support, information and research, we look forward to working with Australian, state and territory governments, clinicians, researchers, heart kids, heart kids parents and the broader CHD community in progressing the implementation of key recommendations of the Action Plan and continuing to grow the scope and reach of our programs and services for the benefit of Australian children and adults with and impacted by CHD.

Jan McClelland, AM
Chairperson

Rob Lutter
Chief Executive Office



OUR YEAR IN REVIEW HIGHLIGHTS

Teen Camp 2018

held in
Queensland

**Team HeartKids
Website**
Launched

**HeartKids
Education Days**
focusing on
Adult CHD

**Inaugural Jaidyn
Stephenson luncheon**
Collingwood
Football Club

HeartKids Gala Ball
Celebrating our
40th Birthday in Perth

**National Congenital
Heart Disease Survey**
Paper published

**The National Strategic Action Plan for
Childhood Heart Disease**
was launched by the
Australian Government on
International Congenital
Heart Disease Day.
\$26 million in funding allocated
to support the plan

JULY AUG SEPT OCT NOV DEC JAN FEB MAR APR MAY JUNE

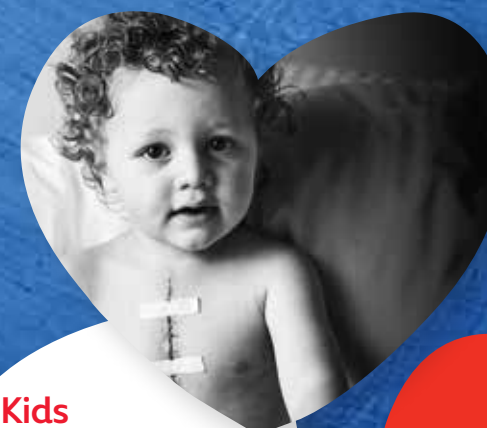
**HeartKids Two Feet and
Heartbeat Charity Walks**
22 communities nationally
with 3,500 participants raising
\$290,000 for research

New CEO appointed
Rob Lutter joins
HeartKids

HeartKids Super Boss Day
raises **\$313,000** with
236 corporate
CEOs and leaders
participating

Noosa Triathlon
Official Charity
Hero partnership
announced

**HeartKids
Show Your Heart 2019**
raised **\$410,000** with
\$1.5million donated media
to raise much needed
awareness of congenital
heart disease



OUR IMPACT

ADVOCACY



National Strategic Action Plan for Childhood Heart disease launched
With \$26 million investment to support the Action Plan.

\$20M

allocated to supporting ongoing research into congenital heart disease causes and impacts as part of the Government's Medical Research Future Fund.

\$6M

to be allocated to HeartKids over 6 years to support the other key areas of the Action Plan.

INFORMATION



67

people assisted with referrals to other agencies

7

education days with 141 attendees

55

families attended regional clinics

15

Fact Sheets developed or updated

5,300

resources distributed
(focus on digital information)

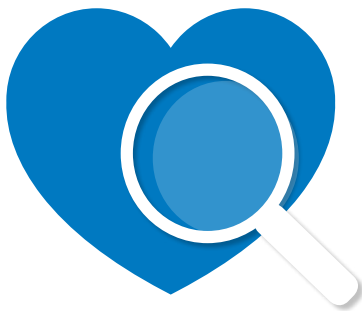
148,000

visits to the website (42% increase)

60,000

social media followers

RESEARCH



The National Congenital Heart Disease Survey completed, and results published

\$20M

over 5 years to be provided from the Medical Research Future Fund – Congenital Heart Disease funding.

SUPPORT



15

HeartKids Support Workers employed in nine hospitals

7,300

people living with or impacted by CHD supported

330

Registered Volunteers throughout Australia

230

bereaved families supported

2,350

active members in the private support group

220

in the MyHeart Teen group



MEET OUR LEADERS



Janette McClelland
Chairperson

Jan McClelland AM is a company director with more than 15 years' governance experience as chair and non-executive director in government, commercial, industry association and not for profit enterprises across a range of industry sectors.

Janette 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 and a Director of Stewart House Preventorium. She is also a member of the Board of the Circular Economy Innovation Network, Local Government NSW Audit and Risk Committee and the NSW Judicial Commission Audit and Risk Committee.

Janette was awarded a Member of the Order of Australia in the 2015 Australia Day Honours for significant service to a range of education, business, social welfare and community organisations, and to public administration.



Beverley Barber
Director

Beverley Barber is an experienced Executive and Non-Executive Director with a background spanning a range of industry sectors including the private sector. Beverley is a Director with Deloitte and throughout her career has worked across State, Federal and Local Governments. She has worked with ASX listed companies and small to medium enterprises and was a Board member on the HeartKids Australia Board and more recently on the South Australia Board.

In addition to experience in business transformation, organisational design, leadership and culture, Beverley holds qualifications in management and public policy and has significant public policy and governance proficiency and a wealth of knowledge and experience in politics and Government Relations. Beverley is committed to the development and growth of HeartKids and has worked with many businesses to help them resolve the most complex issues and achieve success. Beverley is also a member of the Finance and Audit Committee.



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. In June 2015, Jayne was appointed as Caretaker Chief Executive Officer of HeartKids Australia and led the integration process from the HeartKids federated structure to HeartKids Ltd. Jayne is now a Director of HeartKids and Chair of the Development Advisory Committee.

Jayne is an experienced company director with broad cross-functional expertise including key Executive roles in Finance, Sales, Commercial and Customer Relations. 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.



Jared Brotherston
Director

Jared has over 15 years' experience as a director and company secretary in both Australia and New Zealand. A construction barrister by training, Jared has held company secretarial and general management roles in postal services, construction and transport and logistics. He has consulted to numerous resources and oil and gas mega projects in and around Australia. More recently, Jared has held senior commercial roles in contracting and procurement and supply chain management for major mining entities.

Currently, Jared is Commercial Manager of the Southern Ports Authority, with responsibility for Bunbury, Albany and Esperance Ports.



David Celermajer
Director

David Celermajer AO 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 and Clinical Director at The Heart 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 Australian Academy of Science since 2006 and Commonwealth Health Minister's Award for Excellence in Health and Medical Research, for outstanding lifetime contribution in 2002.

Prof Celermajer has extensive experience as a Board director in the not for profit sector. He has been on the Board of HeartKids Ltd since 2016. He was on the Board of the Menzies School of Health Research from 2009 to 2017 inc. He serves as a Trustee for the Sir Zelman Cowen Universities Fund.



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.



Sami Glastonbury

Director

Samantha Glastonbury is Marketing professional with 15 years' experience nationally across several industries with more recently taking a keen focus on consulting to the Food and Health industries. Samantha is also heart mum to Francis who was born with a congenital heart disease and also has special needs. Since the birth of her son, Samantha has developed a passion for consumer advocacy and health reform.

Samantha and her family have been actively involved in fundraising and raising awareness for HeartKids and has now sat as a non-executive director on the state and now national board. Samantha is honoured to be contributing to HeartKids Limited and is dedicated to raising national awareness for HeartKids to support families on their journeys.



Prof. Ruth Salom

Director (Resigned - 01/10/18)

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.



Anthony Mahady

Director (Resigned - 01/10/18)

Anthony is an experienced lawyer, having practised in both Australia and the UK, primarily in financial services law. He is currently responsible for 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, one of which suffers from a congenital heart condition. Anthony is also a member of the Programs and Services Advisory Committee.



Lisa Selbie

Director

Lisa 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.



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.



Ken Murphy

Director (appointed Jan 2019)

Ken has over 20 years of experience as a qualified Company Director/Chairman across multiple industries including Health and Community Services in both the Not For Profit and Private sectors along with CEO and MD level experience in many industries.

Ken is also a current/past member of various Government, Business, and Community Committees and Taskforces. He brings capability with Corporate Governance, Finance, Risk Management, Strategic and Operational Development, Human Resource Management, Company Restructures, Mergers & Acquisitions, Project Management, Community and Stakeholder Engagement, Funding, Problem Solving, Innovation, and Change Management. Ken is the father of a heart kid Oliver (2018 Toowoomba Ambassador - Two Feet & a Heartbeat.)



Stuart Dinnis

Director (Resigned - 06/08/18)

Experience Stuart Dinnis is a Fellow of CPA Australia, Member of the AICD and started his career in audit and risk management. For the past decade, he has held senior roles within Virgin Airline businesses in Australia and the USA and was the Managing Director of the Frequent Flyer program. Stuart was responsible for some of the first ever airline partnerships with the likes of Uber and AirBnB, lead the launch of the world first Visa Velocity travel card and significantly involved in the strategy to re-position Virgin Australia. His career also includes General Manager roles in Telecommunications and Property.

Stuart is heart dad to one of his twins, daughter Olivia.



Simone Wright

Director (appointed Jan 2019)

Simone is a Director with Pearson Australia Group and is an experienced Executive Director with a background in High Tech Manufacturing, Fast Moving Consumer Goods, Architecture, Financial Services, Publishing and Education sectors.

She has worked extensively in reporting to Boards on matters of risk and compliance and was a member of the HeartKids Steering Committee for the Action Plan. In addition to experience in strategic human resources management, organisational design, leadership capability, employee experience, wellness and skills development, Simone has qualifications in business management and the new world of work.

As a parent of a heart child Simone is committed to the purpose of heart kids and ensuring a successful HeartKids Ltd.

CHILDHOOD HEART DISEASE

Why it is a national health priority



Willow Age 6 mths

Many people are unaware of congenital 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 heart disease that in reality covers a wide range of conditions.

Congenital heart disease incorporates a group of abnormalities of the heart and is a general name for any type of malformation of the heart, heart valves or major blood vessels which are present at birth. Defects can range from simple to complex and can occur alone or in groups, depending on how the heart has developed.

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 65,000 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. There are an increasing number of adults with congenital heart disease who are not well served by the existing health care system. Unfortunately, 4 young lives are still lost each week to congenital heart disease.

HeartKids has a commitment to work across the life span.

Gaining a better understanding of the entire spectrum of congenital heart disease, the number of people living with congenital heart disease, and the total burden of disease across the disease continuum is imperative to patients and those responsible for treating them, including health policy makers, ultimately delivering not just better, but sustainable care.

“HUGE shoutout to Heartkids who have supported my niece’s loving family of three adorable Heartkids with the love and care which is second to none. You guys do an amazing job both looking after these families and in your fundraising events too and are all to be highly commended, you are a massive part of their lives and they’re all so much better for all your kindness and Love.”

Thank You Blessings
– Nance (Heart kid family member)

ADVOCACY

OUR OBJECTIVES

- A National Congenital Heart Disease Action Plan is endorsed by Government **Achieved and strengthening**
- HeartKids receives government funding as necessary to maintain and grow its services footprint **Partially achieved and continuing as a priority**
- Financial support for people impacted by congenital heart disease in particular NDIS and Carers Benefits (or similar) is achieved **Not achieved and continuing as a priority**

HeartKids is the voice of all Australians living with and impacted by congenital heart disease and our HeartKids Advocacy and Engagement Plan was successful in delivering long awaited recognition of congenital heart disease as a national health priority.

The National Strategic Action Plan For Childhood Heart Disease (Action Plan)

Culminating in months of consulting with the many clinicians, researchers, ‘heart kids’, parents and carers of ‘heart kids’, policymakers and members of the community, HeartKids along with the Minister for Health, The Hon Greg Hunt, launched the Action Plan on the 14th February 2019 with a total funding commitment from the government of **\$26 million**.

The Federal Government will provide \$20 million for medical research into the genetic causes of CHD, prevention and treatment options. A further \$6 million will help HeartKids implement the recommendations of the National Strategic Action Plan for Childhood Heart Disease over the next 6 years.

The Action Plan is the first nationally-coordinated effort to tackle CHD and provides direction and guidance to transform care so that it is lifelong, holistic, person-centred and family-centred.

"Heartkids have been wonderful we lost our grandbaby Chelsea last week and they have been so supportive of our daughter Natalie and Sean. We look forward to fundraising for HeartKids in the near future."

Linnette
Heart angel grandparent



INFORMATION

OUR OBJECTIVES

- In consultation with specialist clinicians and service providers, conduct ongoing awareness and information campaigns to create greater understanding of congenital heart disease **Achieved and strengthening**
- The reach of our information and support programs increases **Achieved and strengthening**

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.

HeartKids provides support for parents of children with congenital heart disease in many ways. From high quality information and in-hospital support, to peer to peer mentoring connecting parents in a similar situation.

HeartKids 1800 HELPLINE

The HeartKids 1800 Help Line – **1800 432 795** – has supported hundreds of parents and adults answering non-clinical / medical requests for information and increasingly connecting callers with a range of government and non-government support organisations.

In total 67 people were referred to other services including mental health groups. Those who used the service reported a high degree of satisfaction with both the information and the service itself.

Fact Sheets

Fifteen fact sheets were updated and uploaded onto the website. These cover various topics from the basic facts on CHD to exercise and CHD. Since tracking was put in place in October 2018, we have had over 4,700 fact sheets downloaded.

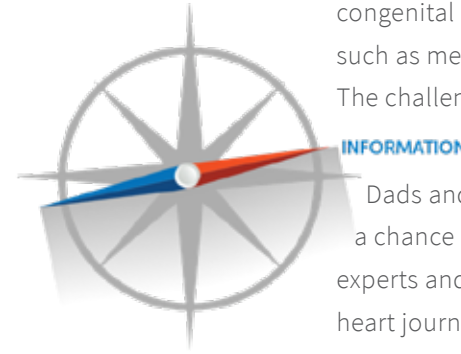
Website and Social Media

There have been over 148,000 sessions to the HeartKids website an increase of 42% over the prior year with an average of 3 pages per session been viewed. Social media also continues to grow with almost 60,000 followers across our platforms. The Private Support groups are well received with 2,350 active members in the general support group and 220 in the MyHeart Teen group.

HeartKids Information Days

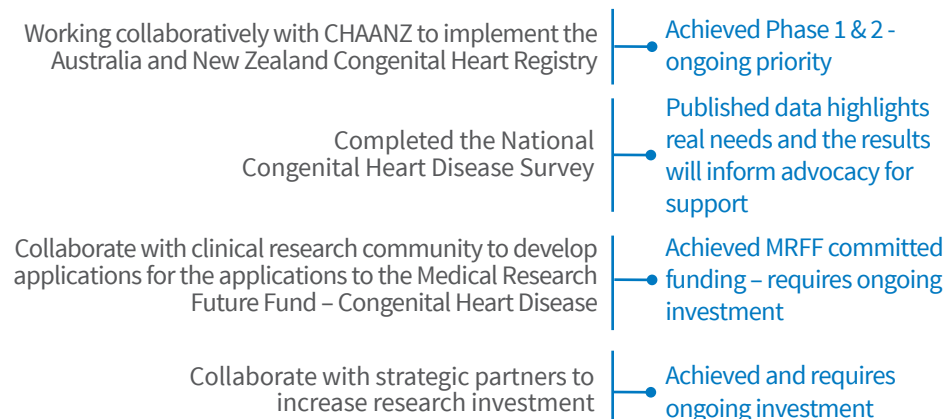
Adult Education Days were held in October 2018. The Focus was on adults living with congenital heart disease. The sessions covered personal lived experiences and included topics such as mental health and well-being, sexual health, intimacy, relationships, and pregnancy. The challenges of living with CHD.

Dads and bereaved dads education day was held in Adelaide in May 2019. The session was a chance for our heart kid dads to talk with a senior paediatric cardiologist, mental health experts and other fathers and grandfathers, to help them to continue to support their families heart journeys now and into the future.



RESEARCH

OUR OBJECTIVES



Congenital Heart Alliance of Australia and New Zealand CHD Registry & Survey

Tracking the long-term changes in those living with congenital heart disease will now be possible thanks to a new Australian first registry, supported by HeartKids. Congenital heart defects are often associated with babies and children, but the disease now affects more young people and adults who are either living longer due to medical advancements or being diagnosed with the disease later in life.

The joint initiative is led by CHAANZ (Congenital Heart Disease Alliance of Australia and New Zealand) funded by HeartKids with the support of The Kinghorn Foundation and The Pinnacle Charitable Foundation, to provide a better understanding of the impact, treatment and outcomes for an estimated 65,000 - 90,000 people living with congenital heart disease.

The National Congenital Heart Disease Registry has now established two pilot sites, at the Royal Prince Alfred Hospital in Sydney and the Royal Children’s Hospital in Melbourne, and has already accomplished preliminary work at sites across Australia and New Zealand.

The National Congenital Heart Disease survey is a vital part of understanding the burden of the disease in adults living with congenital heart disease.

The recently published results of this survey indicated the challenges of transitioning from the paediatric health systems to adult health system care.

Strange, G., Stewart, S., Farthing, M., Kasparian, N.A., Selbie, L., O’Donnell, C., Ayer, J, Cordina, R and Celermajer, D. Living With, and Caring for, Congenital Heart Disease in Australia: Insights From the Congenital Heart Alliance of Australia and New Zealand Online Survey. Heart, Lung and Circulation (2018) xx, 1–7 <https://doi.org/10.1016/j.hlc.2018.12.009>

Prof Geoff Strange highlighted: *“These contemporary, self-reported, Australian data reveal the burden of living and caring for CHD from an adult’s perspective. Survey respondents highlighted the potential disconnect between paediatric and adult CHD services and suggest an important, unmet need for dedicated health services/community care to cost-effectively manage high levels of health care utilisation coupled with associated psychological distress.”*

This critical survey information will inform our advocacy work in securing more funds and resources to care for those living with the disease. Having greater support and collaboration will help us support the best plan for whole of life care, including planning for the right levels of funding and types of resources required at all the different life stages.

HeartKids and the Medical Research Future Fund for Congenital Heart Disease

After facilitating the development and the successful launch of the first ever National Strategic Action Plan for CHD, HeartKids is committed to supporting research which aligns with the important Research Priorities identified in the Action Plan by the clinical, research, government and patient stakeholders.

The Action Plan highlighted key research areas that will have the greatest impact on whole-of-life care of those living with CHD:

- Understand the genetic causes of, and predisposition to, CHD to provide support for those impacted by CHD
- Prevent neurodevelopmental and mental health complications
- Understand the impact of prenatal and postnatal factors affecting the health of children born with CHD and their families
- Measure longitudinal impact and inform practice with the National Congenital Heart Disease Registry
- Explore the role of exercise and increased activity in reducing the impact of CHD

Over the past two years, HeartKids has worked with the CHD community and government to secure the largest single investment in congenital heart disease research in Australia’s history.

The Medical Research Future Fund – Congenital Heart Disease was announced in 2019 to support research priorities identified in the Action Plan, to provide \$ 20 million over 5 years. HeartKids has worked with a number of CHD-specialist research groups to contribute to, and support, consumer input on research, facilitate contact and interaction with patients and families, and assist with dissemination of the results to the HeartKids community.

HeartKids Research Program acknowledges and appreciates the financial assistance of

- The Kinghorn Foundation and Perpetual Trustees
- The James and Jutta Lauf Foundation
- Kiwanis Charitable Foundation
- Angior Family Foundation
- GWA Griffiths Estate

HeartKids Research Partners – Conquering Childhood Heart Disease together

Australian Centre for Heart Health - The Sydney Children’s Hospitals Network
 Royal Prince Alfred Hospital - The Royal Children’s Hospital Melbourne
 The University of NSW - The University of Queensland
 Murdoch Children’s Research Institute Centenary Institute
 Victor Chang Cardiac Research Institute - The University of Western Australia
 Federation University Australia Queensland Children’s Hospital
 Grace Centre for Newborn Intensive Care, Westmead Children’s Hospital
 The University of Sydney



Providing support to our families is central to the HeartKids vision. We provide dedicated, quality support services and information to parents, young people, adults and Heart Angel families. Our aim is to provide guidance and support through the lifetime journey of our HeartKids community.

SUPPORT

OUR OBJECTIVES

HeartKids’ programs are accessible	Partially achieved and strengthening
User and partner satisfaction with our services remains high	Achieved and continuing priority
Provide at least one HeartKids Support Worker in every major paediatric care hub	Achieved and continuing priority

HeartKids Support

Our Support Teams across the country are passionate and dedicated to providing direct support to heart kids and their families in hospital, post discharge, and when back in their own communities.

Our Support teams achieve this by assisting parents when their child is diagnosed with congenital/ acquired heart disease and throughout their lifelong journey, bereaved parents and families, infants, children, young people, young adults and adults with:

Information – practical information and education opportunities about the lifelong journey of living with congenital/acquired heart disease

Referrals – ensuring access to relevant services, and information relating to available local services.

Connection – to other families who understand the realities of living with congenital/acquired heart disease

Direct support – our Support team work closely with families, providing peer to peer emotional support. Practical support is also provided and may include meals assistance, patient travel and accommodation assistance

Community support - enabling families to have the opportunity to share their experiences with other heart kid families, fostering ongoing peer support networks.

Fifteen committed staff are located in Children’s Hospitals in Adelaide, Brisbane, Darwin, Melbourne, Perth and Sydney providing support free of charge. We work in partnership with Hospitals as visiting non-government organisations.

HeartKid’s Support also reaches to regional and rural communities with several Regional Volunteer Coordinators committed to servicing these areas. HeartKids also employs one dedicated Family Support Coordinator in Townsville.

Last year HeartKids Support assisted 7,300 people living with or impacted by CHD across Australia.

HEARTKIDS SUPPORT PROGRAMS

Peers As Mentors

Whilst every family’s congenital/acquired heart disease journey is unique, Mentors offer practical assistance, share their own story, a friendly face, a supportive shoulder and voice on the end of the phone to other HeartKids families.

HeartKids understands the importance of families connecting with other families – to talk to people who really understand the congenital/acquired heart disease journey. The Peers as

Mentors program continues the support provided in hospital by having regular phone calls, catch ups and ultimately being there for our HeartKids families.

Peers as mentors can also facilitate additional support through our Support Team and connect HeartKids families to relevant services once back in their own community.

HeartKids Care Bags

Heart kid families can experience unexpected or emergency stays in hospital. As part of our Support Program, HeartKids Care Bags are provided to families in hospital or travelling regionally for their child’s life saving heart surgery.

Participating hospitals nationally are Westmead and Randwick Children’s Hospital, Perth Children’s Hospital, the Women’s and Children’s Hospital Adelaide, Royal Darwin Hospital, The Royal Children’s Hospital Melbourne and Queensland Children’s Hospital. In 2018/19, 573 care bags were given out to our families with a total value of approximately \$34,380.

Bereavement Support

Tragically, we lose four infants, children and young people each week from congenital / acquired heart disease. Our 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 may provide:

- 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

HeartKids Two Feet and a Heartbeat is a 4km walk, in honour of the four lives lost to congenital heart disease every week in Australia. Walks take place in major capital cities and local communities across the county. The walk concludes with a period of silence in memory of our Heart Angels. Families have the opportunity to come forward and place flowers during this emotional time for reflection.

HeartKids Bead Program

The Heart Beads Program is coordinated by HeartKids in most major children’s hospitals Australia wide.

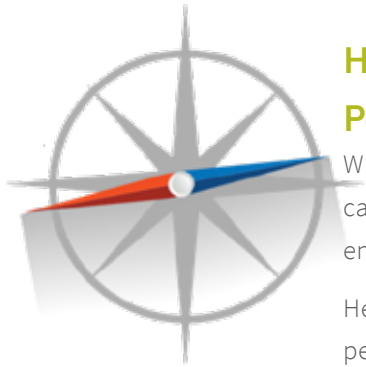
Distinctive beads specific to each procedure or treatment undergone give participating Heart Kids a sense of achievement and help them to tell their own unique CHD story.

We acknowledge the generous donation of the Northern Beaches Social Riders (Sydney) who fund the program’s delivery.

HeartKids Teen Camp

HeartKids’ Teen Camp took place over five days from Monday 9 July until Friday 13 July 2018 at the Gold Coast hinterland venue of Camp Bornhoffen, in Natural Bridge, Queensland. Camp provided 60 teens (13-18 years) impacted by CHD from across Australia the opportunity to undertake life-improving activities in a supportive environment, alongside a vital team of 15 medical professionals and volunteers and was the 11th National HeartKids Teen Camp.

Teen Camp is designed specifically to reduce isolation and boost the self-esteem, emotional, physical and social wellbeing of attendees, thus helping them to navigate their teen years and transition to adulthood cardiac care. It enhances the quality of life and resilience of participants through a range of developmentally-appropriate activities and challenges that they otherwise thought were only for their “healthy” peers. Being inspired and encouraged by new friends with similar challenges, these teens feel a great sense of empowerment and enhanced belief in their future possibilities.



AWARENESS

RAISING COMMUNITY AWARENESS OF THE BURDEN OF CHILDHOOD HEART DISEASE

OUR OBJECTIVES

A diverse revenue base is achieved	Partially achieved and continuing very high priority
HeartKids remains financially strong and sustainable	Partially achieved - an ongoing very high priority
Continue to build multi-year corporate partnerships linked to identified priorities	Partially achieved - an ongoing high priority
Increased funding from Trusts and Foundations	Achieved and strengthening
Increased Government investment in hospital and community care programs	Partially achieved - actively being pursued

HeartKids promotes and advances awareness of congenital heart disease through several community awareness campaigns. Three national campaigns were delivered in 2018 - 2019 to ensure all Australians understand the burden of disease and the impact on all people living with or impacted by congenital heart disease. Below is a snapshot of our major campaigns.

HeartKids Sweetheart Day/Show Your Heart 2019

Post Sweetheart Day 2018 a significant review of the campaign took place. It was recommended that the campaign be expanded from one day to the month of February to allow for people to engage with the campaign and included a fresh new look and feel. Community fundraising was to be the primary focus. Show Your Heart this February campaign was kindly developed by the team at Hullsbosch.

The campaign achieved \$410,000 in revenue and over \$1.5million in pro bono media coverage. Social media, PR and outdoor outperformed the previous year. Awareness of congenital heart disease was significantly boosted throughout February and the announcement of the National Strategic Action Plan for Childhood Heart Disease add a highlight. With thanks to Virgin Money Australia, our Show Your Heart partner who matched donations up to \$50,000.

HeartKids Two Feet & A Heartbeat Charity Walk

This community walk continues to grow with over 20 sites nationally with 3,500 participants raising \$292,000. The walk this year evolved to be a 4km walk representing the four lives lost to CHD or participants could do it twice for the eight babies a day born with CHD. 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 heart disease, red by those walking in support and white by those walking in memory of a Heart Angel.

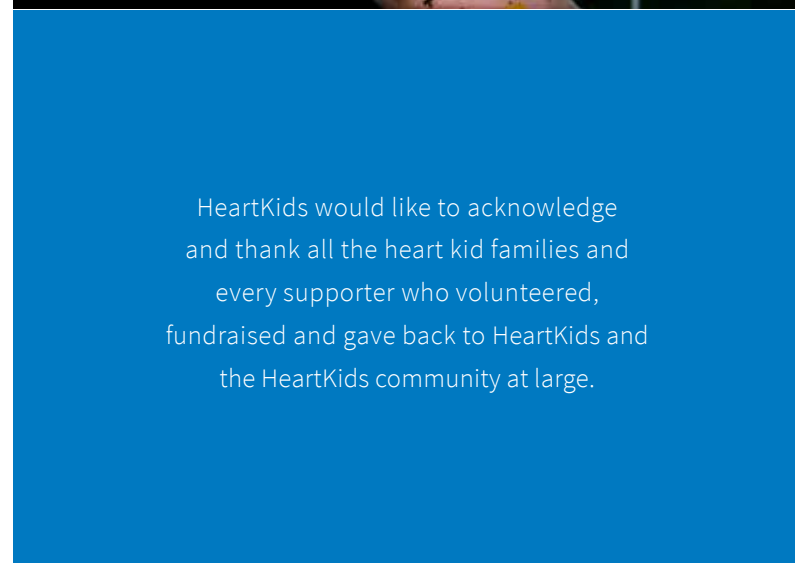
HeartKids annual charity walk unites us and fosters a true sense of community.

HeartKids Super Boss Day 2019

May 31st was Super Boss Day, HeartKids national day of action for corporate leaders and business owners to raise funds for HeartKids programs. This year 236 Super Bosses from every corner of Australia participated raising \$313,000.

Now in its fifth year Super Boss Day is proving a very effective and fun corporate engagement campaign that captures the attention of employers and employees alike.

A special mention to Drakes Supermarkets who contributed over \$110,000 to the campaign.



FINANCIALS



Izzy Age 7

FINANCIAL REPORT AT A GLANCE

Statement of Profit or Loss and Other Comprehensive Income For the Period Ended 30 June 2019

	2019 \$	2018 \$
Revenue earned	4,321,827	4,983,711
Other income	31,950	48,435
Fundraising expenses	(717,752)	(673,510)
Program, research, grants and support expenses	(744,729)	(1,295,535)
Salary and wages	(2,423,459)	(2,686,448)
Finance and administration	(95,228)	(124,856)
Other expenses	(469,051)	(735,554)
(Deficit) for the period	{961,442}	{483,571}
Total comprehensive income for the period	(96,442)	{483,757}

For the complete Financial Statement visit heartkids.org.au/who-we-are/our-purpose/governance

"I've found this group not only helpful and supportive but so needed through our journey as I don't feel so alone and are connecting with people who know exactly how I feel! The HeartKids page support workers are so lovely and have been there with me since the beginning of our journey when I found out my Bub had a heart condition at my 20wk scan, then through my daughter's birth and her first and second surgery meeting me in the hospital for a chat and supporting me in every way they possibly could. We will forever be so grateful for all support we've received and for all the friendships made through HeartKids and in the hospital."

Nicole
Heart kid parent

GOVERNANCE

OUR OBJECTIVES

- Collective accountability for strategy | Achieved and a continuing priority
- Ethical decision making in governance, program, resources, finance and fundraising applied | Achieved and a continuing priority

Role of the Board of Directors

The role of the Board is defined by the HeartKids Limited Constitution, which is the legal instrument guiding the organisation.

The Board's role is to ensure a range of strategies that support people impacted by congenital heart disease is achieved. 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;
- recruitment of the CEO and setting executive remuneration;
- ensuring the establishment and ongoing review of a suite of policies;
- establishing and monitoring the achievement of organisational goals;
- ensuring the integrity of internal control and management information systems; and
- ensuring compliance with applicable laws and reporting requirements.

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

All Board members, staff and volunteers operate in line with a Code of Conduct – *Every Day Every Way*.

Board processes

To assist in the execution of its responsibilities the Board of Directors has established several 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 Zealand (CHAANZ) Sub Committee.

Board planning framework

Our Strategic Planning framework includes:

- a national corporate plan, incorporating three-year performance targets;
- an annual business plan and budget relating to the corporate 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 policy manuals and guidance material.

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.

Composition of the Board of Directors

The Board is a skills-based Board and is broadly representative of the congenital heart disease community. It includes cardiologists, health sector professionals and policy analysts, medical researchers, legal, accounting and human resources specialists, marketing and fundraising professionals, 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 five 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.

Critical Risks and Mitigations impacting HeartKids

The strategic risks being actively managed by the Board and leadership team include

- The ongoing sustainability of the organisation to deliver quality services to people affected by CHD across Australia through increased reliance on revenue from philanthropic donations and a diversity of fundraising initiatives, in a highly competitive environment for funding contributions. The Board closely monitors the financial performance of the organisation monthly to ensure the company has sufficient reserves to meet short and long-term liabilities.
- Increasing awareness of HeartKids and childhood heart disease within government and the broader community to attract increased funding and investment. The Board has approved an advocacy strategy to engage with Australian, state and territory governments to raise awareness of the prevalence and impact of CHD and to gain funding support for core service priorities, workforce and infrastructure needs and research priorities.
- Attracting and retaining talented staff and volunteers. The Board values the dedication and commitment of our staff and recognises the importance of developing their skills to meet the challenges of service delivery and fundraising. A plan is now in place to develop staff and deploy volunteer support to meet identified gaps in skills.

"Families of kids with heart conditions know the importance of such organisations. One of the best support networks, which is committed at delivering the best assistance to the families who are going through rough patches of life for their loved ones. Truly amazing!"

Naveed
Heart kid parent

Lilli Age 1



Xander's Story

Meet Xander our 2019 & 2020 face of the Show Your Heart Campaign. Xander's heart didn't form correctly in the womb and this has meant that this little boy has had some of the most complex heart surgery that it is possible to have. Xander had his first surgery at two days old. Just before he turned one, he had his first major heart surgery and his first birthday was spent in hospital. He has since had a pacemaker fitted to keep his heart in rhythm.

For almost 12 months the most basic activity was exhausting for him and the energy levels required to perform the most basic task was a challenge for him. Xander also displayed signs of post-traumatic stress and anxiety which was evident when he had to see doctors or visit the hospital.

Xander is doing really well since his surgeries two years ago. He is a happy, loving, kind, energetic and thriving three-year-old. He loves all things 'construction' but importantly, sees joy in all aspects of life. He has experienced so much pain and suffering but continues living as though nothing is wrong.

Without his shirt on, all of his scars are reminders of his ordeal and they are a symbol of the strength and courage and bravery he showed while fighting for survival.

HeartKids has provided a lifeline to the whole family throughout their journey. They've supported by providing advice through their helpline and face-to-face meetings, provided care bags to support the often lengthy and expensive hospital stays and provided Xander with his own heart beads as a visual to keep track of the journey Xander has been on. Each bead signifies a major procedure and brings reminders of what Xander went through and will be something for Xander to treasure when he is older to help him understand the gravity of what he survived.

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