

ANNUAL IMPACT REPORT

2021



HeartKids



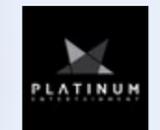
THANKYOU

HeartKids very much appreciates the support of our partners large or small. We thank you for your donation of time and funding to enable us to achieve our vision. With your help congenital heart disease has gone from an invisible disease to a national health and research priority.

CORPORATE PARTNERS



SUPPORTING PARTNERS



GOVERNMENT SUPPORT

Australian Government
Department of Health

West Australian Government
Department of Health

Northern Territory
Department of Health

City of Melbourne

South Australian Government
Department of Human Services
Business Victoria

TRUSTS AND FOUNDATIONS

Kinghorn Foundation via
Perpetual Trustees

Marian & EH Flack Trust

Edwards Lifesciences

The James & Jutta Lauf
Foundation

QBE Foundation

QLD Gambling Fund

UnLtd Foundation

MGA Whittles Community
Foundation

Dimmick Charitable Trust

The Lin Huddleston Charitable
Foundation

Lotterywest

McCusker Charitable Foundation

MAJOR SUPPORTERS AND GIFTS IN MEMORY

NATIONAL

IKEA Australia

NSW | ACT

Carroll Household

Dedes Waterfront Group

Janelle Green

Northern Beaches Social
Riders Club

Sofia's Battle

Trees Adventure

VIC | TAS

Bignell Household
Stannards Accountants
and Advisors

Oz Hog Melbourne

Branded Burgers and Bar
Chicks for Charity Foundation

AFL Gamers

QLD

AP Eagers Foundation Limited

WA

All Saints College

Lynn Yager

Fennell Tyres International
Atlas Copco Power Technique
Australia

Riding Free Brothers

Motorcycle Club

TransAlta Energy Australia

SA | NT

Henschke Household

Katerina Iliopoulos

IN-KIND SUPPORTERS

Crown Entertainment Ltd (Victoria)

O'Brien Icehouse (Victoria)

Melbourne Sea Life Aquarium

Corporate Challenge

IFLY Melbourne

David Strassman/Ted E. Bare

Harry Potter and the Cursed
Child cast

Melbourne Star Observation Wheel

Special Children's Christmas Party

Variety Children's Charity
(Christmas and Zoo day)

Grill'd

Ian Sharp Jewellers

Jessie Norman-Linke

White Lady Funerals

Hastings Deering

Precious Time Fabric and Quilts

Tewantin Noosa Lions Club

Oakover Grounds

Nikola Estate

Wildcats

Keiko Uno Jewellery

Class Act Performers

Dr Richard Walley - Aboriginal
Productions

Peter Madson

Royal Wolf

Stelios Jewellers

Slater Air

MEDIA PARTNERS

DDB (Sydney)

Initiative Media

Lightbulb

UnLtd

Write Away

HEARTKIDS ACTION PLAN IN-KIND SUPPORT

A/Prof Gary Sholler AO as the
Co-chair of the Australian National
Standards of Care for Childhood-
onset Heart Disease (CoHD).

Standards of Care CoHD Steering
Committee and Action Plan
Advisory Committee members.

- Dr Lisa Selbie
- A/Prof Luke Burchill
- Prof Michael Cheung
- Shakira Donovan
- Caitlin Elliott
- Prof Nadine Kasparian
- Kristie Molloy
- A/Prof Prem Venugopal

Working Group Chairs and Co-chairs

- Dr Julian Ayer
- Dr Rachael Cordina
- Evelyn Culnane
- Prof Michael Cheung
- Shakira Donovan
- Dr Lucas Eastaugh
- Caitlin Elliott
- Prof Jeffery Fletcher
- A/Prof Robert Justo
- Prof Nadine Kasparian
- Dr Andrew Kelly
- Dominique Morsman
- A/Prof Mugur Nicolae
- Dr Yishay Orr
- Elle Pendrick
- Dr Jim Ramsay
- Dr Bo Remenyi
- A/Prof Prem Venugopal
- Prof Robert Weintraub
- Dr Gavin Wheaton

Young Persons' Digital Advisory Group:

- Anthony Mentasana
- Sarah Purdom
- Jaden Dixon
- Thomas Henderson-Smith
- Caitlin Johnson
- George Clarke
- Jamie Curmi
- Erin Ferguson
- Cassandra Tichanow
- Rebecca Peters
- Michelle Vink

HEARTKIDS MISSION

HeartKids is the only national not-for-profit organisation solely focused on supporting and advocating for all people impacted by congenital or childhood acquired heart disease, one of the largest causes of infant death in Australia.

Our support is a commitment for life because there is no known cure. People with congenital heart disease face unique challenges throughout their entire life.



Audrey 3 years



VISION

(where we want to be)

Every child, teenager and adult in Australia with congenital or childhood acquired heart disease has a fighting chance to live a long, healthy and fulfilling life.



PURPOSE

(why we exist)

To make a real and lasting impact for the Congenital and Childhood acquired Heart Disease (CHD) community.



VALUES

(how we do what we do)

- H: Helpful and caring
- E: Excellent and united
- A: Adaptable and innovative
- R: Respectful and empowering
- T: Tenacious and brave



APPROACH

(what we do)

- HeartKids is the only national Australian charity to:
- Support, inform and educate families throughout their whole CHD journey; AND
 - Advocate for the needs of all people impacted by CHD; AND
 - Drive funding to unite researchers, clinicians, heart kids, families and communities through world-leading research and action programs; AND
 - Harness the passion of the CHD community for greater impact.



SUPPORTING HEART KIDS THROUGH LIFE

On behalf of the Board of Directors and staff of HeartKids Limited (HeartKids), I am pleased to present HeartKids' Impact Report for the year ending 30 June 2021.

This report summarises our fifth year of operation as a consolidated national entity providing lifelong support for more than 65,000 Australian babies, children, teens, and adults affected by Congenital Heart Disease, and their families and carers.

There is no doubt that 2020/2021 has been a tough year for all in Australia. Covid-19 has significantly impacted not only HeartKids but all in our community. For the first time in our over 40-year history, we were not able to provide face-to-face support within the hospital environment or within the community, and many of our physical support events, such as our teen camp, were either cancelled or postponed. In these challenging times, our staff have shown perseverance, resilience, and imagination, adapting to new ways of working remotely, finding new ways to provide on-line services and support to our community, and exploring new ways of fund raising. The organisation has shown itself to be adaptive and agile, continuing to deliver excellent service to the HeartKids community and meet fundraising goals in challenging times.

In January 2021, we welcomed Fiona Ellis as the new CEO of HeartKids. Fiona joined us from St John Ambulance, managing commercial operations, service development and customer service. Prior to this she had spent 20 years in senior management and CEO roles including CEO of Variety, The Children's Charity (NSW). Her wealth of knowledge in the charity sector is already proving to be a great asset for HeartKids.

In March 2021 the Board and CEO undertook a series of independently facilitated strategic planning sessions and developed a renewed vision, purpose, values and approach for HeartKids. In pursuit of our vision that every child, teenager, and adult in Australia with congenital or childhood acquired heart disease has a fighting chance to live a long, healthy, and fulfilling life, the Board determined six (6) strategic priorities for the next three (3) years to guide the organisation towards future service excellence and financial growth.

These strategic priorities are:

1. Develop partnerships and strategic relationships to increase reach and service delivery to our communities and leverage opportunities for advocacy and research.
2. Become the trusted leader in the provision of information and education on HD in Australia.
3. Grow the HeartKids impact in regional, rural, and remote communities.
4. Strengthen, grow, and diversify fundraising and revenue sources.
5. Improve the transparency of reporting, compliance, and risk management across the organisation.
6. Develop an agile, adaptive, and innovative organisation by growing the skills, capacity and capabilities of our staff and volunteers.

During 2020/2021 HeartKids made excellent progress in implementing key initiatives of the National CHD Action Plan to deliver significant outcomes for the HeartKids community, clinicians, and allied health professionals.

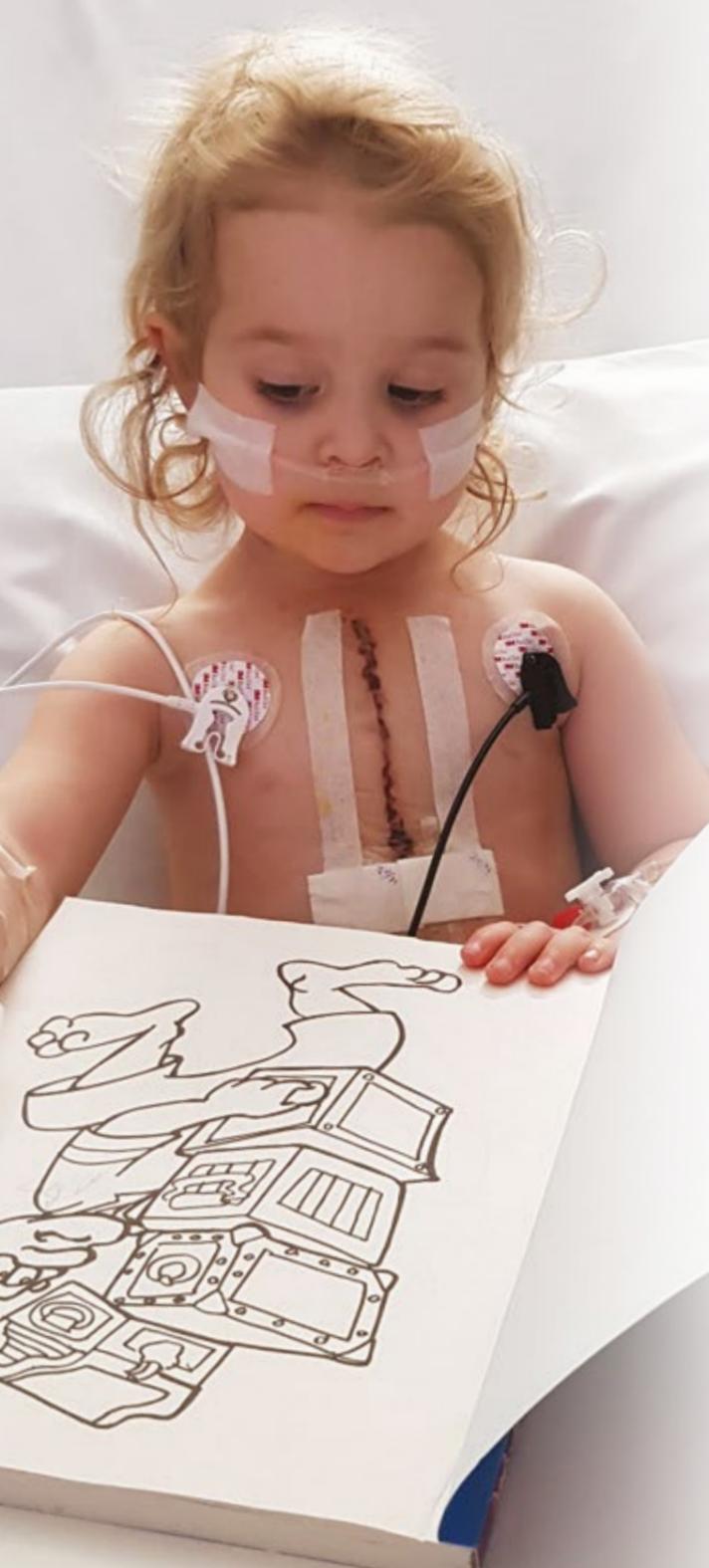
- We established a Young Persons Digital Advisory Committee and worked on the development of a smart phone app designed to assist young people with CHD to better manage their condition and engage with their health care more independently.
- In collaboration with hundreds of health professionals and consumer community representatives, we progressed development of the first Australian National Standards of Care for Childhood-onset Heart Disease.
- We developed new consumer resources including five My Heart Story videos and two Aboriginal and Torres Strait Islander Community Stories.
- We commenced planning of three teen camps including a camp for Aboriginal and Torres Strait Islander teens with CHD or Rheumatic Heart Disease (RHD).

Building on the close partnerships we have established with clinicians, researchers, government and consumers and our significant achievements in implementing key recommendations of the Action Plan, we look forward to continuing to work with Australian, state and territory governments, clinicians, researchers, heart kids, heart kids parents and the broader CHD community in growing the scope, reach and impact of our programs and services for the benefit of Australian children and adults with and impacted by CHD.

This report highlights only a small part of the significant amount of work completed by our very dedicated team of staff, board of directors, volunteers and supporters this year. While we have adapted well to the current environment providing services to families in need, there is still much to be done to address the unmet demand for programs and services.

I would particularly like to acknowledge the commitment and diligence of the directors of the HeartKids Board and to thank them for their time, expertise, support and significant contribution to the governance of HeartKids. 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 purpose and goals this year and the years to come.

Jan McClelland, AM
Chairperson



Kayleigh 3 years



Pria 2 months

MESSAGE FROM THE CEO



I am delighted to be with HeartKids as the new CEO and I look forward to a bright future together, supporting everyone impacted by congenital or childhood acquired heart disease., and raising funds so that we can provide more support and new programs in the years ahead.

I am pleased to see that our staff, communities, and families have adapted to the changes that COVID-19 has made to our lives and our world, we have found positive elements of change, especially in the way that we communicate, work and support one another. As an organisation, HeartKids has been very innovative in creating new campaigns and event opportunities which encourage both physical and online participation. We have used technology to ensure that we can remain connected with our families and deliver service and support to everyone, near and far. The restrictions of COVID-19 have taught us that we can support you in many new and different ways and if anything, 2020 has made us stronger in our resolve to be with you when you need us. As we continue to support CHD families, we have had to grow stronger over the last twelve (12) months.

The amazing community support for one another has not changed and it is so wonderful to see you sharing your wonderful stories across social media. Your passion continues to raise awareness of CHD and the audience grows daily. I am really looking forward to the opportunity of meeting many of you and your family members at local events in the near future. As we move forward, I have no doubt we will be presented with exciting new challenges and opportunities. With your help and support we will continue to grow and flourish, engaging new sponsors, building new corporate partnerships, and developing new service programs as an organisation that works with and for its community,

HeartKids has grown so much over recent years. We thrive on the energy and engagement that we get from the CHD community, and I would personally like to reaffirm the ongoing commitment of HeartKids to provide and grow the support, advocacy and research that we provide to you and your families. The coming year will see HeartKids continue to grow with innovative new support programs and events. I would like to thank the Board of HeartKids for their ongoing support, our wonderful corporate partners, trusts and foundations, and most importantly the amazing HeartKids staff who deliver service excellence to the HeartKids community with great passion, dedication and care.

Fiona Ellis
CEO

OUR YEAR IN REVIEW HIGHLIGHTS



Community Survey

Launched to HeartKids Community and healthcare professionals to understand information gaps.



HeartKids Website & Database

New look website and database launched to improve user experience.



120,000 HeartKids Information Brochures

Distributed nationally to **3,600** medical practices and clinics.
Tonic TV Ad in 1,560 GP Practices



Annual Jaidyn Stephenson Luncheon

A successful event under Covid-19.



WA Gala Ball

A successful Gala Ball was held after numerous postponements.

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

HeartKids Two Feet & A Heartbeat Charity Walk

Significantly impacted by Covid-19 restrictions
3,218 participants raising **\$340,000**.
New Virtual program launched



New CEO

Fiona Ellis joins HeartKids.

HeartKids Sweetheart Day 2021

Raised awareness of CHD and HeartKids with **\$3.6 million** donated media.



Be a Hero for HeartKids Day

Raised **\$360,000** under Covid-19 restrictions.



OUR IMPACT



Ryker 3 months

1,770

Specific Covid-19 related support services provided

132

Health professionals and consumers contributed to developing the Standards of Care.

269

Support sessions for bereaved families

166

Participants involved in Action Plan committees

120,000

Information brochures distributed

65,000

Social media followers

MEET OUR LEADERS



Jan McClelland
Chairperson

Jan is the inaugural Chairperson of HeartKids Limited. Appointed in 2016, Jan has led the development of HeartKids as the national organisation providing services and support for children and people affected by Childhood Heart Disease (CHD). She also led the development of the National Strategic Action Plan for CHD, resulting in government recognition of CHD as a national strategic health priority.

Jan is an experienced Executive, Chair and Non-Executive Director, with leadership and governance experience spanning government, commercial, and 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 of the University of New England, Chair of the Superannuation industry's Gateway Network Governance Body, Chair of the Life Insurance Code Compliance Committee, and a Director of Stewart House. Jan is also an independent chair and a member of government and other industry sector audit and risk committees.

Jan 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.



Jayne Blake
Deputy Chair

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 and Deputy Chair of HeartKids and Chair of the Development Advisory Committee and Nominations Committee.

Jayne is an experienced company director, with broad cross functional expertise including key executive roles in finance, sales, commercial and customer relations. In addition to the HeartKids Board, Jayne is also Chair of the Board of Fitness Australia since 2018 and chair of Marine and Civil Maintenance since July 2020. 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.



Beverley Barber
Director

Bev is an experienced Executive and Non-Executive Director with a background spanning a range of industry sectors including the private sector.

Bev currently owns and manages her own consulting practice and has previously worked in the Big4 consulting firms. Throughout her career, she has worked across State, Federal and Local Governments.

In addition to experience in business transformation, organisational design, leadership and culture, Bev is a Graduate of the Australian Institute of Company Directors and holds qualifications in management and public policy. She is also a Fellow of the Governor's Leadership Program and has significant experience in politics and government relations. Bev has been involved with HeartKids on both State and National Boards for over 6 years and is committed to the development and growth of HeartKids Ltd. Bev is also a chair of the Finance and Audit Committee.



Jared Brotherton
Director

Jared has been involved with HeartKids since 2011 – first, as a Director and then Chairman of HeartKids WA, then as a Director of HeartKids Australia (before and during the transition of that entity to the current federated structure) and is now Director and Company Secretary of HeartKids.

Jared also has over 20 years' experience as a Director and Company Secretary in both Australia and New Zealand and is a Graduate of the Australian Institute of Company Directors and a Fellow of the Governance Institute of Australia. A construction and medico-legal barrister and solicitor by training, Jared has held company secretarial and senior management roles in postal services, construction and transport and logistics industries. He has consulted to numerous resources and oil and gas mega projects in and around Australia.

More recently, Jared held senior commercial roles in contracting and procurement and supply chain management for major mining entities.

Currently, Jared is Head of Procurement for the Southern Ports Authority, with commercial responsibility for Bunbury, Albany, and Esperance Ports.



David Celermajer AM
Director

David Celermajer AM 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.

David has extensive experience as a Board director in the not-for-profit sector. He has been on the Board of HeartKids Australia 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. He also has extensive experience in medical research administration, having been the Foundation Director of Research at RPA Hospital in Sydney and the Chairman of the Research Committee for the Heart Foundation of Australia from 2005-2011.



Rohan Geddes
Director

Rohan has over 30 years of experience in employment and payroll matters. He is a Partner at PricewaterhouseCoopers, where he leads the National Payroll Advisory and Employment Services practices, helping employers re-engineer their processes to ensure they are getting the most value out of their payroll function and are paying the right amount of their employment obligations.

Rohan has also worked in Australia and the US, providing personal tax assistance to high net income wealth individuals and expatriates. Rohan is a Heart Kid.



Lionel Henderson
Director

Lionel Henderson is an experienced Company Director and manager of large-scale research engagements. He is a Director of Business Development & Commercial with CSIRO, where he has developed the framework for several research alliances and collaboration frameworks, including public – private partnerships, and has managed CSIRO’s involvement in multiple CRCs. Lionel has managed the licensing for a range of CSIRO’s technologies domestically and internationally and has recently returned from a USA posting. He has also been a member and Chair of a number of external committees for CSIRO. Lionel is an experienced Company Director, having been a Director or Company Secretary for several CSIRO joint ventures, since 2004.

Prior to joining CSIRO, he managed a horticultural biotechnology company for 10 years, which had a significant international business and large intellectual property portfolio. Lionel has a science background and has worked in the commercialisation of new technologies since 1988.

As the grandfather of a heart kid, Lionel is committed to the success of HeartKids Ltd



Ken Murphy
Director

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 and 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.)



Elle Pendrick
Director

Elle has over ten years’ experience successfully prosecuting significant agendas at the highest level of government, including as a Ministerial Adviser. She has worked in Australia and Cambodia on state and federal government health policy and program issues, and has a Masters of International Health.

Elle directly contributed to the development and launch of the National Action Plan for Childhood Heart Disease and the HeartKids blog page. She also raises the awareness of HeartKids and life as an adult with CHD through her own social media platforms. As a heart kid she is committed to seeing HeartKids achieve its full potential.



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.

Lisa 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.

Lisa is an adjunct lecturer with Johns Hopkins University MS/MBA Biotechnology Program developing and delivering on ground and online courses, Senior Lecturer at the School of Biotechnology and Biomolecular Sciences UNSW serves on the NSW AusBiotech Committee, and previously was Chair of HeartKids Australia and the Research Advisory Committee.

Lisa is currently Co-chair of the Australian National Standards of Care for Childhood-onset Heart Disease project.



Matthew Tognini
Director

Experience 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 condition.



Simone Wright
Director

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 Government Action Plan. In addition to experience in strategic human resources management, organisational design, leadership capability, employee experience, wellness and skills development, Simone has post graduate qualifications in business management and the new world of work.

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



ACTION PLAN IN NUMBERS

10

participants in the Australian National Standards of Care for Childhood-onset Heart Disease Steering Committee

132

members of the Australian National Standards of Care for Childhood-onset Heart Disease Working Groups across the following domains: Cardiology, Cardiac Surgery, Consumers, Large Centres, Mental Health, Neurodevelopmental, Nursing, Priority Populations, Research, Regional Centres, Small Centres and Transition

10

participants (clinicians and young people) on the Young Person Digital Advisory Committee for the development of the UpBeat phone app.

14

participants on the Action Plan Advisory Committee to guide delivery of the National Strategic Action Plan for Childhood Heart Disease

Haddie 4 months

ADVOCACY

OUR OBJECTIVES

At HeartKids our vision is to make a real and lasting impact for the Congenital Heart Disease (CHD) community. We are continuing our work to advocate for all in the community and delivering the National Strategic Action plan for Childhood Heart Disease.

THE NATIONAL STRATEGIC ACTION PLAN FOR CHILDHOOD HEART DISEASE (Action Plan)

The CHD 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-centered. Proudly led by HeartKids, the implementation of the CHD Action Plan is now underway.

National Strategic Action Plan

The CHD Action Plan project kicked off in April 2020, thanks to several years of advocacy by HeartKids and discussions between government, health professionals involved in CHD care, patients and their families, all with a vision to reduce the impact of childhood heart disease in Australia and achieve the goal that people with childhood-onset heart disease live longer, healthier and more productive lives.

Projects that are currently underway include:

- National Standards of Care for Childhood-onset Heart Disease: The Standards of Care will provide the first national standards and a framework to ensure all Australian patients and families affected by CHD receive excellence in comprehensive cardiac care. The first draft of the standards of care were published for public consultation in October 2021
- Health Professional Education: The Education Project will produce a suite of resources for health professionals that support integrated, quality health care for all stages of the CHD care pathway. Resources will be developed with a wide variety of expert content contributors, will be targeted to priority learning areas and will include specific resources for primary care. The Health Professional Education Portal will be launching in 2022.
- Teen Camps: Teen Camps provide an opportunity for young people aged between 13-17 years with a heart condition to connect with others experiencing a similar journey, learn self management skills, develop new friendships, and create ongoing peer support networks. Teen Camps will kick off with a camp in December 2021 on the Sunshine Coast for Aboriginal and Torres Strait Islander teens aged 13-17 with CHD, followed by camps in April 2022 in Perth and September 2022 in Sydney for all teens with CHD.
- UpBeat Teen App: UpBeat is an app designed for young heart kids (15 to 19 years) who are starting to manage their lives and health care more independently. It is a tool that helps users to engage with the transition process and the self-management of their condition, while connecting them to relevant support services and resources. UpBeat is currently in pilot phase, and will be available for download early 2022.
- Research: Funding to the Medical Research Future Fund facilitates research to provide new diagnoses and improved treatment options to reduce the burden of CoHD on all those affected, health professionals.



Adam 5 years and Luke (sibling) 3 years

INFORMATION

OUR OBJECTIVES

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

HEARTKIDS 1800 HELP LINE

The HeartKids 1800 Help Line – 1800 432 795 – has supported hundreds of parents and adults answering non-clinical requests for information and increasingly connecting callers with a range of government and non-government support organisations. In total 171 (up from 91 last year) people requested direct support with 89 people referred to other services including mental health groups, social workers and accommodation facilities. Those who used the service reported a high degree of satisfaction with both the information and the service itself.

FACTS SHEETS

The HeartKids fact sheets were updated and streamlined to be more accessible to our community. Two new Aboriginal & Torres Strait Islander resources were added along with a number of videos in our new “MyHeart” series that showcases various people in the community and how they overcame some of the key challenges faced by all living with the impact of CHD. All these videos are available on the website in a dedicated resource and information section. Importantly, information on COVID-19 and CHD was uploaded and continuously updated. Also undertaken in the past year was the distribution of 120,000 HeartKids information brochures to 3,600 medical practices and clinics.

WEBSITE AND SOCIAL MEDIA

The website was revamped and relaunched in January 2021. Despite this we maintained the number of visits year on year (130,000 FY21 vs 128,000 FY20). The site was optimised so consumers could have a better user experience and obtain information with just a few clicks. The number of pages viewed per visit decreased which is a direct result of this optimisation while time spent on the site increased.

Social media is an integral way we communicate with our community. Our audience continues to grow with over 65,000 followers across our platforms. The private support groups are well received and have also grown with 3,021 active members in the general support group and 265 in the My Heart Teen group.



William 4 months

HEARTKIDS RESEARCH PARTNERS

Conquering Childhood Heart Disease together:

- Australian Cardiovascular Alliance
- Australian Centre for Heart Health
- Centenary Institute
- Federation University Australia
- Heart Research Institute
- Murdoch Children's Research Institute
- Queensland Children's Hospital
- Royal Prince Alfred Hospital
- The Children's Hospital at Westmead
- The Royal Children's Hospital Melbourne
- The Sydney Children's Hospitals Network
- The University of NSW
- The University of Queensland
- The University of Sydney
- The University of Western Australia
- Victor Chang Cardiac Research Institute

RESEARCH

HEARTKIDS AND CONGENITAL HEART DISEASE RESEARCH PRIORITIES AND SUPPORT

After facilitating the development and successful commencement of the first ever National Strategic Action Plan for CHD (Action Plan), 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.

RESEARCH FUNDING

HeartKids' advocacy work contributed to the allocation in 2020 of \$18 million in funds from *The Medical Research Future Fund* to support research into congenital or acquired heart disease and the impact on families over the next 3 years. The research objectives include:

- preventing neurodevelopmental and mental health complications;
- understanding the impact of prenatal and postnatal factors affecting the health of children born with CHD and their families; and
- exploring the role of exercise and increased activity in reducing the impact of CHD.

RESEARCH PRIORITIES

HeartKids continues to collaborate with the CHD clinical and patient community to identify research priorities which deliver positive outcomes and insights people with CHD. Currently, HeartKids is facilitating the development of the first Australian National Standards of Care for Childhood-onset Heart Disease. The project is the culmination of over a decade of advocacy from the combined voices of HeartKids patients and families and the CHD healthcare community. Importantly, The Standards also recognise the critical role and requirements of multidisciplinary research in understanding the causes, triggers and mechanisms of disease, and optimising outcomes for patients, and will provide key recommendations for support of CHD research in the future.

RESEARCH SUPPORT

HeartKids has worked with a number of CHD-specialist research groups to contribute to, and support, consumer input on research, assist in raising awareness for study recruitment, facilitate contact and interaction with patients and families, and assist with dissemination of the results to the HeartKids community.

Patients, families and carers (consumers) are central and integral to our identification and support of research with the greatest impact, and have been a key voice in the development of the National Standards of Care for Childhood-onset Heart Disease. A key partnership HeartKids has recently initiated is with the Australian Cardiovascular Alliance (ACVA), a key organisation which includes the very highest quality cardiovascular research bodies and scientific societies, individual researchers, industry and non-government organisations in Australia. This partnership positions HeartKids to leverage these key interactions to increase CHD-research through collaboration and advocacy.

HeartKids Grants in Aid Research Program acknowledges and appreciates the financial assistance of:

- The Kinghorn Foundation and Perpetual Trustees
- Kiwanis Charitable Foundation Australia



Finlay 6 months

SUPPORT

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.

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, in their own communities and throughout their lives.

The past year provided some unique challenges for our support teams and our HeartKids community given the difficult circumstances of the coronavirus crisis and the resulting isolation for many of our families. With our support teams unable to access the hospitals for a period of time or provide in community support, we have been innovative in communicating and supporting our community virtually throughout this time.

Our support teams have continued to assist parents when their child is diagnosed with congenital/acquired heart disease and throughout their lifelong journey, they have also supported families with, infants and young children, young people, young adults, adults and bereaved parents and extended families 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. HeartKids support staff collaborate with allied health services, connect families with the NDIS, social services, indigenous liaison and other community organisations and bereavement services.

Connection – to other families and peers 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 or near 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 charitable organisations.

HeartKids support also reaches regional and rural communities with Regional Volunteer Coordinators committed to providing support in these areas. HeartKids also employs dedicated Family Support Coordinators in Townsville and Alice Springs.

Last year HeartKids support had 7,994 support occasions across Australia.



Liddywoo 20 years

As mentioned earlier, the HeartKids support programs within hospital were impacted by COVID-19 and as a result support was delivered in a virtual environment for the first time. This innovation allowed the support team to continue to reach and support our HeartKids community through online meetings, information sessions and even Harry Potter readings by stage actors unable to work during the pandemic which were very well received.

During the coronavirus crisis a significant amount of support was delivered online and over the phone to our Community. Specific virtual support instances totaled 1,342 including virtual morning teas, COVID-19 specific emotional support cases and COVID-19 financial stress cases

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, be a friendly face, a supportive shoulder and voice on the end of the phone to our 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 during hospital stays and assists HeartKids staff with community support 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 programs, 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. Due to the coronavirus impact our care bag numbers were understandably down from the previous year.

HeartKids Financial Assistance Program

We understand the significant financial, emotional and physical impact that congenital/acquired heart disease causes our HeartKids families.

Thanks to our donors and corporate partners HeartKids provides a Financial Assistance Program for referred families experiencing extreme hardship.

Bereavement Support

Tragically, we lose four infants, children and young people each week to congenital or 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.



Joshua 2 weeks

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
- Organised events to connect families

HeartKids provided direct support to 269 bereaved families.

The HeartKids Two Feet & a Heartbeat event 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 country. The walk includes 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 Heart Beads 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 help to fund the program.



Wyatt 1 year



Leon 6 months

AWARENESS

HeartKids promotes and advances the awareness of congenital heart disease through community awareness campaigns. Three national campaigns were delivered in 2020/2021 to ensure all Australians understand the burden of the disease and the impact on all people living with congenital heart disease or heart disease acquired during childhood and their families. Below is a snapshot of our major campaigns.

HEARTKIDS SWEETHEART DAY

In 2021, the Show Your Heart campaign reverted back to the 14th February – Sweetheart Day or International Congenital Heart Defect Awareness Day, once again becoming the key focus date of the campaign.

Despite the significant challenges faced during this time, we managed to raise over \$300,000 in revenue.



2021 saw the introduction of *Things can change in a heartbeat* awareness campaign that was delivered as part of the Sweetheart Day campaign to drive awareness of congenital heart disease and the impact it has on families.

The campaign was well received and an outstanding result of over \$3.6 million in media coverage at no cost to HeartKids was achieved. TV, radio, outdoor, out-of-home, and PR out performed the previous year. Awareness of congenital heart disease increased by 7% (cause awareness) and awareness of HeartKids increased by 4%. Significant engagement and awareness was boosted throughout February which is the main objective of this campaign.

As a HeartKids family said after viewing Things Can Change in a Heartbeat campaign:

" I just saw your ad campaign tonight and WOW. Having a baby girl born 10 weeks early with serious heart related complications, that comparison style imagery was amazing.

I trust it's one that will raise greater awareness to people who are clueless about the hardship of such situations.

Just WOW.

It's like a lifted burden when something like that is made public to help those who have a healthy baby finally understand that not everyone is that fortunate.

It's a wake up call for parents to no longer take an easy birth for granted.

THANK YOU! "



Neeah Bin Swani 21 months

HEARTKIDS TWO FEET & A HEARTBEAT CHARITY WALK

This community walk was impacted by COVID-19 restrictions with Victoria, New South Wales, parts of Queensland and the ACT physical events moved to a virtual option. Despite this, 3,200 participants raised close to \$340,000.

They all walked 4kms (whether around their neighborhood or at an organised event), 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.

HERO FOR HEARTKIDS DAY

Friday 18 June was our *Be a Hero for HeartKids Day* (formally Super Boss Day) event. This national campaign targeted businesses, schools and the community to dress up as superheroes and raise funds and awareness for HeartKids.

The Hero for HeartKids event this year was still impacted by the coronavirus restrictions and uncertainty of work practices in each State and the resulting impact on businesses all over Australia. Despite the challenges we were very pleased to have Heroes dressing up for HeartKids from every corner of Australia helping raise \$360,000.

Now in its seventh year *Be a Hero for HeartKids* is proving to be a very effective and fun corporate engagement campaign that captures the attention of employers and employees alike.

HeartKids would like to acknowledge and thank all the businesses, childcare centres, schools, heart kid parents and supporters who sponsored and donated to their Heroes. A special thank you to Drakes Supermarkets management and staff who actively participate in this event across all their stores in South Australia and Queensland and raise a significant amount of money for HeartKids every year.



FINANCIALS



Haddie 4 months

FINANCIAL REPORT AT A GLANCE

Statement of Profit or Loss and Other Comprehensive Income For the Year Ended 30 June 2021

	2021 \$	2020 \$
Revenue	4,335,483	3,170,645
Other income	547,113	330,134
Fundraising expenses	(582,336)	(278,445)
Program, research, grants and support expenses	(930,678)	(426,433)
Depreciation and amortisation expense	(105,669)	(55,008)
Salaries and Wages	(2,684,135)	(2,131,497)
Finance costs	(123,180)	(64,695)
Other expenses	(286,851)	(264,248)
Surplus before income tax	169,747	280,453
Total comprehensive surplus for the year	169,747	280,453

For the complete Financial Statement visit heartkids.org.au



Ryker 3 months

GOVERNANCE AND MANAGING RISK

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 role of the Board is to ensure the achievement of a range of strategies that support people impacted by congenital heart disease. 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 (CEO). Responsibilities are delineated by formal authority delegations.

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;
- Nominations and Remunerations 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 set of strategic objectives with clear goals over three (3) years
- an annual business plan and budget relating to the strategic objectives;
- a reporting framework against KPIs;
- delegated authorities, recorded in a policy framework, from the Board to the CEO and staff.
- a risk management plan; and
- Board skills matrix reviewed, and regular Board evaluation process undertaken.



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. The organisation also maintains a Board skills matrix to ensure that there is a broad cross section of skills and it also directs professional development for Board members.

COMPOSITION 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, 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 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 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 directs 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 the staff and recognises the importance of developing their skills to meet the challenges of service delivery and fundraising.

Isla 5 years, Aaliyah 7 years and Kobi 12 years



Aurora 7 months

THE CARROLL FAMILY'S HEART JOURNEY

"There is something wrong with your baby's heart' are not words you imagine you'll hear at your 20-week scan", shares Julia, mother of now 1 year old Aurora.

"This was the day our lives changed forever".

Aurora was born with a rare heart condition called Double Outlet Right Ventricle, a malformation of the pulmonary artery and aorta.

Julia explains, "At 6 weeks old, Aurora underwent lifesaving open heart surgery. Her recovery was complicated, but she overcame this enormous challenges with the help of her incredible medical team". And if navigating this path wasn't difficult enough in its own right, the Carroll family faced doing so in the height of NSW COVID-19 lockdown, isolated and without the face-to-face support of their loved ones as they remained by their daughter's bedside in hospital throughout her months of recovery without the possibility of visitors, or the opportunity to introduce Aurora to her grandparents.

"We are so grateful for the care and expertise of Aurora's medical team, and the staff at HeartKids for their unwavering support during those tough times. Aurora is now thriving, and we could not be prouder and more grateful for her."

"During our darkest days in hospital, we longed to return home, and we were reminded of the simple things in life – like a walk, a coffee with friends, family time – things we often take for granted. Those simple pleasures mean so much when your world is turned upside down".

For Aurora's first birthday in June, the family celebrated with friends at their local park for a Community Walk in celebration of Aurora, and all that they have overcome together over the past 12 months.

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