



ANNUAL
IMPACT REPORT
2020

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 Governments
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

Flack Trust

Edwards Lifesciences

HBF Health Foundation

Stan Perron Foundation

James & Jutta Lauf Foundation

QBE Foundation

Variety SA

Channel 7 Telethon Trust

Amway One By One Foundation

Perpetual Trustees

UnLtd Foundation

MGA Whittles Community Foundation

Dimmick Charitable Trust

Kevin Irwin Memorial Foundation

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IKEA Foundation

Kinghorn Foundation via Perpetual Trustees

Yinhawangka Charitable Trust

Kiwanis Charitable Foundation Australia

Golden Stave Foundation

Uniting Church Foundation

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

NATIONAL

Origin Energy Limited

QLD

Anthony Dunn

Benjamin Ferdinand

Queensland Community Benefit Fund

Timothy Melville

NSW | ACT

Barney Bedelis

Bunnings NSW

Hornsby North Community Care Association

Jodie Heterick

Northern Beaches Social Riders Club

Rosemarie King

VIC | TAS

Allport Bequest

Biggin and Scott Richmond

Jet Couriers

MarketPlace Fresh

Matthew Steer

Collingwood Football Club

SA | NT

Telethon SA Home Lottery

WA

All Saints College

HBF Community Engagement

Peter Madson

Platinum Entertainment

John Bignell

Lynn Yager

Scott Baxter

TAG Wealth Solutions

MEDIA PARTNERS

DDB Australia

Initiative Media

Lightbulb

UnLtd

Write Away



HEARTKIDS MISSION

Ollie 19 months

We are HeartKids, the only national body dedicated to supporting all infants, children, young people and adults affected by congenital (or acquired during childhood) heart disease (CHD).

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 during childhood) 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

People with congenital and acquired childhood heart disease live longer, healthier and more productive lives.

PURPOSE

We support heart kids and those impacted by congenital or acquired childhood heart disease through life.

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

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 2020.

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.

This report summarises our fourth 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.

In a year that has been marred by drought, floods, bush fires and Covid-19, 2019/2020 was a year of consolidation for HeartKids as we adapted to many changes impacting the broader community and worked towards ways to better service all those impacted by CHD.

After the announcement of the National Strategic Action Plan for Childhood Heart Disease (the Action Plan) by Minister Greg Hunt in February 2019, funding from the Commonwealth Department of Health for several key focus areas from the Action Plan was awarded to HeartKids Ltd, with work beginning in April 2020.

Building on the strong foundations established in the development of the National Strategic Action Plan for CHD, the close partnerships we have established with clinicians, researchers, government and consumers, and our significant achievements in advocacy, support, information and research, we continue to grow the scope and reach of our programs and services. We look forward to working with Australian, State and Territory governments,

clinicians, researchers, heart kids, heart kids parents and the broader CHD community as we implement the key focus areas of the Action Plan and deliver key programs and services for the benefit of Australian children and adults with and impacted by CHD.

During 2019/2020 we have continued to raise awareness of CHD through education sessions, publications, media exposure and information services. We are 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 Medical Research Future Fund is currently managing research projects into CHD and has allocated \$18 million to researching congenital or acquired heart disease and the impact on families.

Throughout 2019/2020 our dedicated team of State Managers and staff across Australia has continued to provide direct support to heart kids and their families, in hospital, after discharge, and when back in their own communities. In 2020, the team has had to adapt our services to provide more one-on-one and group on-line support as we found ourselves for the first time in 40 years out of the hospital environment for extended periods of time due to Covid-19. It has been a trying time for all in our community but together we have remained, and will continue to remain, strong.

Our Teen Camp which was held in January 2020 in Victoria almost did not go ahead due to the bushfire crisis, but teenagers and young adults with CHD from across Australia came together and were given the opportunity to develop their communication and leadership skills in a safe and stimulating environment. They also developed lifelong support networks to assist them in their transition from paediatric to adult care. Young People's transition into adult care continues to be a focus in the years ahead.

Our fundraising efforts to help support the work we do have been significantly impacted in 2019/2020. The Show Your Heart campaign was impacted by the bushfires experienced across Australia in late 2019/early 2020. Our annual Super Boss Day Campaign this year was heavily impacted by the coronavirus restrictions and uncertainty experienced in each State and the resulting impact on businesses across Australia. However, the team found innovative ways to deliver these campaigns during uncertain times.

This report highlights only a small part of a significant amount of work completed by our very dedicated team of staff, board of directors, volunteers and supporters this year. While we have achieved a lot, there is still much to be done to meet 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 purpose and goals this year and the years to come.

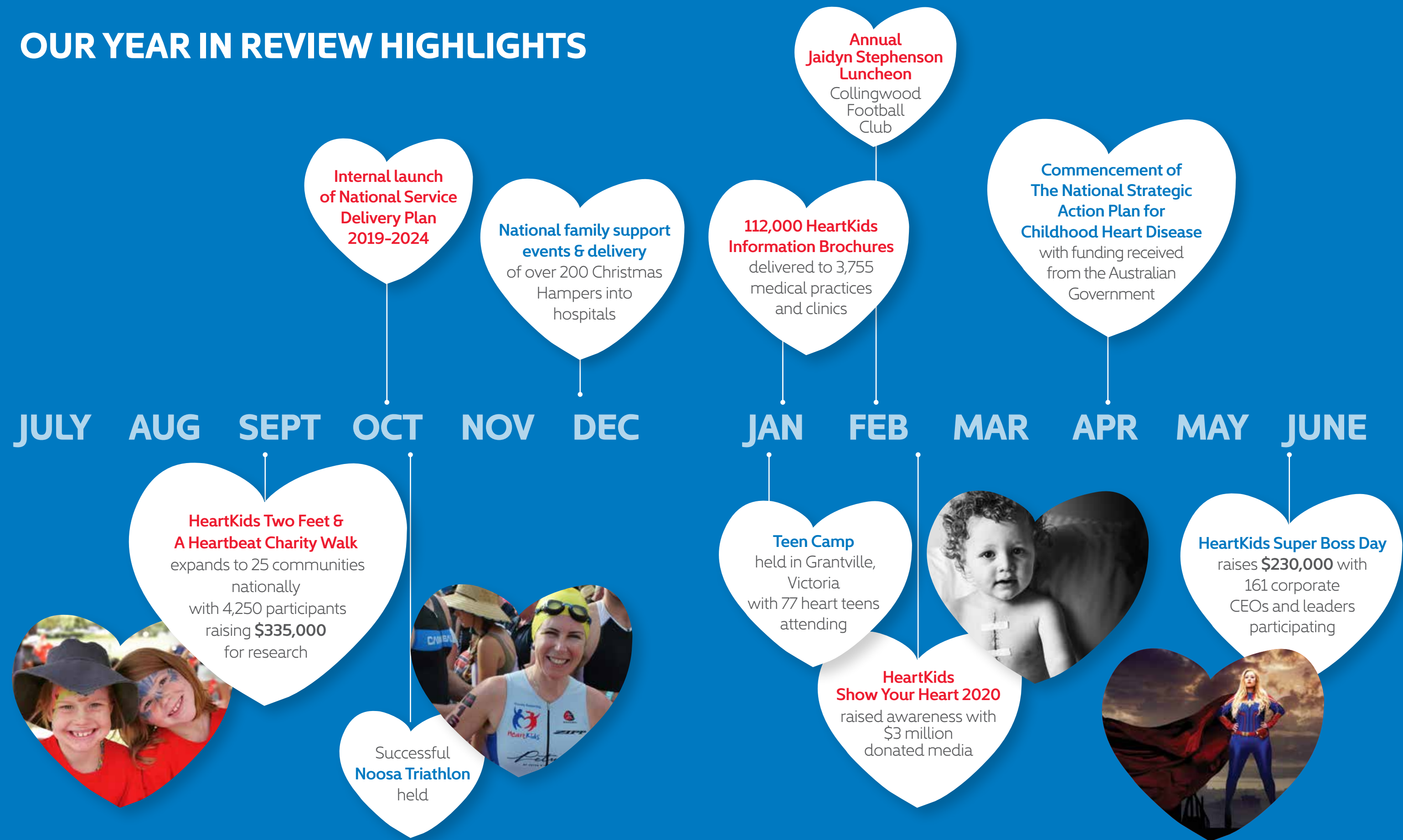
Jan McClelland, AM
Chairperson



Izzy 10 years



OUR YEAR IN REVIEW HIGHLIGHTS



OUR IMPACT

ADVOCACY



Work on The National Strategic Action Plan for Childhood Heart Disease commenced in April 2020, with significant investment from the Commonwealth Department of Health. Advocacy work to date has included:

- Establishing an Expert Steering Committee and larger Advisory Group for the development of the first Australian Standards of Care for Childhood-onset Heart Disease
- Establishing the Action Plan Advisory Group who have committed to continuing to advocate and lobby to ensure that initiatives to address the ongoing challenges in the CHD community are implemented.

HeartKids SA/NT secured a \$50k grant from the NT Health Department and NT Rheumatic Heart Disease Control Program:

- Provide support services in the NT, over a 2-year period, to indigenous teens, supporting them through their Rheumatic Heart Disease journey
- This work is being carried out in partnership with key NT stakeholders, including the Royal Darwin Hospital, Alice Springs Hospital, regional clinics, and the NT RHD Steering Committee.

INFORMATION



91

people assisted with referrals to other agencies

6,095

digital resources downloaded

128,000

visits to the website

61,000

social media followers

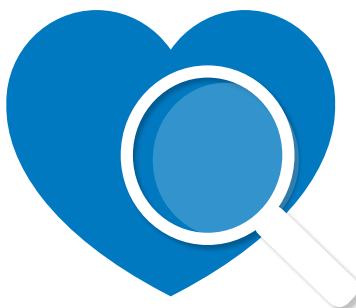
112,000

Heartkids information brochures distributed to...

3,755

medical practices and clinics

RESEARCH



\$18M

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

6

CHD grant recipients' projects will support research to provide new diagnoses and treatment options for those suffering from congenital heart disease.

SUPPORT



15

HeartKids Support Workers employed in nine hospitals

7,994

people living with or impacted by CHD supported

256

bereaved families supported

91

people assisted with referrals

316

COVID-19 emotional support cases

1,002

virtual support instances

57

virtual morning teas

MEET OUR LEADERS



Jan McClelland

Chairperson

Jan McClelland AM is a company director with more than 16 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.

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



Beverley Barber

Director

Beverley Barber is an experienced Executive and Non-Executive Director with a background spanning a range of industry sectors. Beverley 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, Beverley 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. Beverley has been involved with HeartKids on both State and National Boards for over 5 years and is committed to the development and growth of HeartKids Ltd. 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. Jayne 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. 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.



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 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. 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' 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 Pricewaterhouse Coopers, 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 (Until Oct 2019)

Samantha Glastonbury is a 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. Samantha has 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.



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 HeartKids and ensuring a successful HeartKids Ltd.



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 an adjunct lecturer with Johns Hopkins University. MS/MBA Biotechnology Program developing and delivering on ground and online courses, a Senior Lecturer at the School of Biotechnology and Biomolecular Sciences UNSW. Lisa 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 condition.



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 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 (Appointed October 2019)

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.



Lionel Henderson

Director (Appointed October 2019)

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 HeartKid, Lionel is committed to the success of HeartKids Ltd.

ADVOCACY

OUR OBJECTIVES

- | | |
|---|---|
| A National Congenital Heart Disease Action Plan is endorsed by Government | → Achieved |
| HeartKids receives government funding as necessary to maintain and grow its services footprint | → 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 \$24 million.

The Federal Government will provide \$18 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.

Lucy 6 months

NATIONAL STRATEGIC ACTION PLAN – where we are now

After the announcement of The National Strategic Action Plan for Childhood Heart Disease (the Action Plan) by Minister Greg Hunt in February 2019, funding from the Commonwealth Department of Health for several key focus areas from the Action Plan was awarded to HeartKids Ltd, with work beginning in April 2020.

The key focus areas selected by the Department of Health for a three-year period of funding (2020, 2021 and 2022) are:

Standards of Care

Develop authoritative national clinical practice guidelines on CHD for health services and health practitioners throughout Australia. This includes initially developing the National Standards of Care for Childhood-onset Heart Disease, and following on from these, Clinical Practice Guidelines and Workforce and Infrastructure Plans.

Infrastructure

Provide education, training and support for health care professionals. This will include the development of a suite of education modules on priority topics across a variety of mediums for health professionals.

Increase support and targeted resources for the management of CHD in primary care. Working in partnership with relevant health organisations like the Royal Australian College of General Practitioners, the Primary Health Networks nationally and Rural Workforce Agencies, a suite of specifically designed CHD resources will be made available for GPs and Practice Nurses for including in existing chronic disease management mechanisms and processes.

Awareness and Education

Work to increase access to quality, relevant information, education and support, including:

- Enhancing and expanding the existing 1800 HeartKids telephone service to meet community demand
- Delivering culturally appropriate communications, resources and support materials that are accessible and relevant to all people impacted by CHD, with a focus on priority populations
- Developing a national publicly accessible register of qualified professionals and local and national peer groups

Increase the number of young people engaged with transition and ongoing specialist CHD care by:

- Developing an evidence-based mobile phone application that assists young people with CHD in self-management of their condition, with features such as assistance for attending appointments, and engaging with peers, allied health and psychological support during transition
- Delivering two accessible and appropriately resourced teen camps for young people with CHD, with a focus on young people from priority populations (delayed due to COVID-19).



Tariq 6 months

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

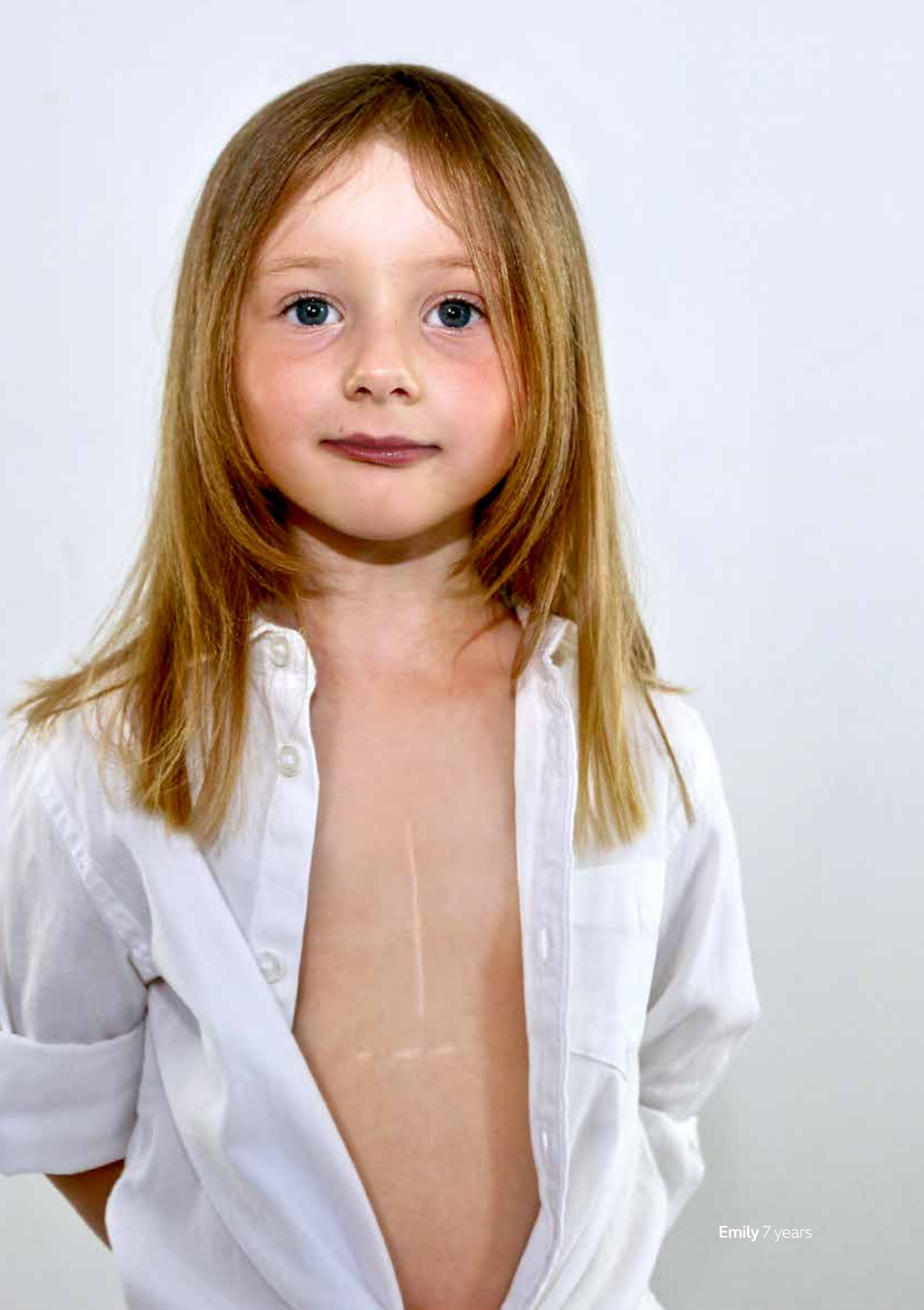
The HeartKids 1800 Help Line – 1800 432 795 – has supported hundreds of parents and adults answering non-clinical / medical requests for information and increasingly connecting callers with a range of government and non-government support organisations. In total 91 (up from 65 last year) people were 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 are available on the website covering various topics from the basic facts on CHD to exercise and CHD. We have had over 6,095 fact sheets downloaded to date. Also undertaken in the past year was the distribution of 112,000 HeartKids information brochures to 3,755 medical practices and clinics.

Website and Social Media

There have been over 128,000 sessions to the HeartKids website with an average of 4 pages per session being viewed. Social media also continues to grow with almost 61,000 followers across our platforms. The private support groups are well received and have also grown with 2,718 active members in the general support group and 256 in the My Heart Teen group.



Emily 7 years

RESEARCH

OUR OBJECTIVES

Working collaboratively with Congenital Heart Alliance of Australia and New Zealand (CHAANZ) to implement the Australia and New Zealand Congenital Heart Registry

• Achieved Phase 1 & 2 - ongoing priority

Enhance community engagement and consumer co-design in developing programs and research

• Achieved and continues to be a priority

Collaborate with clinical research community to develop applications to the Medical Research Future Fund – Congenital Heart Disease

• Achieved MRFF committed funding – requires ongoing investment

Collaborate with strategic partners to increase research investment

• Achieved and requires ongoing commitment

HeartKids and the Medical Research Future Fund for Congenital Heart Disease

After facilitating the development and the successful commencement 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 Medical Research Future Fund is currently managing research projects into CHD and has allocated \$18 million to researching congenital or acquired heart disease and the impact on families.

“An \$18 million investment from the Government will support a further six research projects that aim to reduce the impact of congenital heart disease by investigating new ways to diagnose and treat the condition. Each year in Australia, it is estimated 3,000 babies are affected with congenital heart disease. People with complex and severe congenital heart disease require specialist treatment throughout their life.”

The CHD grant recipients’ projects will support research to provide new diagnoses and treatment options for those suffering from congenital heart disease.

The various projects will align with the National Strategic Action Plan for Childhood Heart Disease, and will target the research priorities in the Action Plan in particular:

- 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, or
- exploring the role of exercise and increased activity in reducing the impact of CHD.

The Grant Recipients are:

University of Sydney	\$3,994,175	An Australian Study of the Outcomes and Burden of Congenital Heart Disease
University of Sydney	\$3,328,569	Congenital Heart Fitness Intervention Trial: CH-FIT
University of Sydney	\$2,081,761	Personalised Pulmonary Valved Conduits: reducing re-operations in CHD
The University of Adelaide	\$3,041,595	Maternal exposures, congenital heart defects, and child development
The University of Queensland	\$3,133,858	Gene Expression to Predict Long-Term Outcome in Infants After Heart Surgery
Queensland University of Technology	\$2,997,256	CHD LIFE+ family-centred care models supporting long-term neurodevelopment

HeartKids provided letters of support and/or partnership agreements as part of the application process. HeartKids Limited supported and/or partnered with the following successful applicants (below).

An Australian Study of the Outcomes and Burden of Congenital Heart Disease

Applicants: Prof David Celermajer AO and Prof Geoff Strange

This project supports the further development and implementation of the CHAANZ Registry to identify outcomes and burden of disease.

Congenital Heart Fitness Intervention Trial: CH-FIT

Applicants: Dr Rachael Cordina and team

The Congenital Heart Fitness Intervention Trial (CH-FIT) being conducted at the University of Sydney is a research project that will investigate the health impact of exercise, and the best way to help adults and children living with congenital heart disease to lead active lives. The project is the largest and most definitive exercise trial ever performed in people living with congenital heart disease.

Gene Expression to Predict Long-Term Outcome in Infants After Heart Surgery

Applicants: A/Prof Schlapbach and team

The proposal is based on a successful cohort spanning across paediatric surgical centres in Australia and New Zealand and utilized genomics technology to improve prediction of adverse short- and long-term outcomes in children under 2 years of age requiring heart surgery. The proposal is unique in following up the largest cohort in the field into school entry age using state-of-the art questionnaires and neuropsychological assessment.

A CHD LIFE+ family-centred care models supporting long-term neurodevelopment

Applicants: Prof Steven McPhail (Academic Lead – AushSI/QUT) and Director of the Queensland

Paediatric Cardiac Service - A/Prof Robert Justo (Clinical Lead – CHQ/UQ).

This project will build on work previously undertaken by members of the Queensland Paediatric Cardiac Service, to expand opportunities Australia-wide. ‘CHD-LIFE’ was developed and implemented as a decentralised model of care for children across Queensland who received surgery for CHD at the Queensland Children’s Hospital. This is an enabling project intended to bring together many experts from a variety of backgrounds (medicine/surgery, nursing, allied health, health economics, implementation science, statistics etc.) to break new ground in considering innovative ways we can organise our health services to provide high-quality, cost-effective, family-centred care for children with CHD and their families.

Holly Williams, HeartKids State Manager is a member of the CHD LIFE Program’s Leadership Group and was previously a Steering Committee member in the collaborative project to establish the CHD LIFE developmental long-term care pathway. HeartKids will partner with the CHD LIFE+ team to ensure the voice of families with lived experience of CHD is central to the development and implementation of care models.

HeartKids Research Initiatives

HeartKids has also 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 Grants in Aid Research Program acknowledges and appreciates the financial assistance of;

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

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 InstituteCentenary Institute
- Victor Change Cardiac Research InstituteThe University of Western Australia
- Federation University Australia, Queensland Children’s Hospital
- Grace Centre for Newborn Intensive Care, Westmead Children’s Hospital
- Heart Research Institute
- The University of Sydney



Tariq 4 days

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.

The past year provided some unique challenges for our support team 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 we have been innovative in communicating and supporting our community virtually throughout this unprecedented situation.

Our support teams have continued to assist 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. HeartKids Support staff collaborate with allied health services, connect families with NDIS, Department of Human Services, indigenous liaison and other community organisations.

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 non-government organisations.

HeartKids 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 had 7,994 support occasions throughout Australia.

As mentioned earlier, the HeartKids support programs within hospital were impacted by COVID-19 and as a result went virtual 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 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 totalled 1,002 including 57 virtual morning teas, 316 COVID-19 specific emotional support cases and 60 COVID-19 financial stress cases. There were also 807 support occasions in our regional areas that were made more accessible through our virtual programs.

Heartkids Support Programs

The first module of the HeartKids Families Program – *Navigating Your New Normal* was developed and commenced in February 2020. The Families Program is a one-day workshop for parents and was developed to provide practical support and coping strategies for families impacted by congenital/acquired heart disease. When a baby or a child is diagnosed with congenital/acquired heart disease a family is forced to adjust their lifestyle and learn to navigate their new normal.

Areas covered in the program include:

Diagnosis	Managing Other People
Managing Family and Siblings	Emotional Wellbeing and Listening Well
Learning to Accept Why	Childcare and School
Grief and Chronic Sorrow	Early Intervention and NDIS
Reducing Isolation	Dealing with Medical Professionals
Navigating Transitions	Social Media
Coping Strategies	Work and Finances

Sadly, due to the coronavirus crisis, HeartKids was unable to roll out the Families Program completely during the financial year.

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 in hospital 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 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. Due to the coronavirus impact our care bag numbers were understandably down from the previous year. In 2019/20 189 care bags were given out to our families with a total value of approximately \$11,340.



Joshua 2 weeks

Bereavement Support

Tragically, we lose four infants, children and young people each week from congenital/acquired heart disease. Our Heart Angels are precious and HeartKid's 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 & 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 country. 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 programs delivery.

HeartKids Teen Camp

The 12th HeartKids National Teen Camp took place from Wednesday 15 January to Sunday 19 January 2020 in Grantville, Victoria. Seventy-seven heart kid teens enjoyed a range of activities and topics including; Indigenous storytelling, nutrition, leadership skills, team initiatives and team building, excursion to Phillip Island Ranger Talk and Penguin Parade, surfing, beach expedition and park ranger guide, mountain bike riding, a high ropes course, low ropes course, bushwalking, junior farming, giant swing, archery, swimming and canoeing. Attendees came from Victoria, Western Australia, Australian Capital Territory, New South Wales, Queensland, South Australia, Tasmania and Northern Territory.

Teen Camp attendees were under the supervision of specialised volunteers and a highly experienced and dedicated medical team. The medical team included specialist cardiologist, doctors, cardiac nurses, ICU nurses, paramedics, emergency nurses, Aboriginal health practitioner, allied health clinicians and community health workers all with specialist experience in cardiac care, intensive care or adolescent health experience. Prior to camp, we organised for specialised training with an all-terrain wheelchair, which was facilitated by the Sherpa Program from Parks Victoria. This training ensured that we were able to provide a greater level of care on camp for those young people who may have previously been unable to attend camp due to issues with accessibility or participation in activities due to inability to walk long distances, fatigue or breathlessness as a result of their heart condition.

Teen Camp provides an opportunity for young people to connect with others who may have experienced a similar journey living with congenital/acquired heart disease, develop new friendships and create ongoing peer support networks that continue long after Teen camp finishes. Importantly, the program aims to promote positive psychosocial and physical outcomes for attendees in a supportive, relaxed, fun and medically safe environment. Teen Camp is based on a youth engagement model which is dedicated to providing the young people attending camp with an opportunity to increase their level of independence, build their own capacity to demonstrate self-management skills, improves social skills, group based life skills, motivation, optimism, self-efficacy, resilience, physical activity and assists in developing their own self-confidence.

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	Achieved continuing to be a 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 2019/2020 to ensure all Australians understand the burden of disease and the impact on all people living with or impacted by congenital heart disease or heart disease acquired during childhood. Below is a snapshot of our major campaigns.

HeartKids Show Your Heart 2020

Show Your Heart 2020 was held for the month of February to allow people time to engage with the campaign. The Show Your Heart campaign was significantly impacted by the Bushfires experienced across Australia in late 2019/early 2020 with charities across the sector losing fundraising income due to the coordinated effort to assist those directly impacted by the unprecedented fires.

Despite the difficult environment, the campaign achieved \$223,000 in revenue and an outstanding result of over \$3 million in pro bono media coverage. Social media, PR and outdoor outperformed the previous year. Awareness of congenital heart disease was significantly boosted throughout February which is the main objective of this campaign.

HeartKids Two Feet & A Heartbeat Charity Walk

This community walk continues to grow with over 25 sites nationally and close to 4,200 participants raising close to \$335,000. The event continues 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 2020

Friday 19 June was our Super Boss Day, our national campaign targeted at businesses, schools and the community to dress up as superheroes and raise funds and awareness for HeartKids.

Our annual Super Boss Day Campaign this year was heavily impacted by the coronavirus restrictions and uncertainty experienced in each State and the resulting impact on businesses all over Australia. Due to the restrictions, we were forced to think outside the box and incorporate virtual options for those unable to hold events and fundraise in person. Essential services were targeted to be involved



including supermarkets and other stores least affected by the coronavirus restrictions. Despite the challenges we were very pleased to have 161 Super Bosses from every corner of Australia participate raising \$232,000.

Now in its sixth year Super Boss Day is proving 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 heart kid parents and supporters who sponsored and donated to their favourite Super Boss. A special mention to Drakes Supermarkets who contributed over \$110,000 to the campaign.



FINANCIALS

FINANCIAL REPORT AT A GLANCE

Statement of Profit or Loss and Other Comprehensive Income For the Period Ended 30 June 2020

	2020 \$	2019 \$
Revenue	3,170,645	4,321,827
Other income	330,134	31,950
Fundraising expenses	(278,445)	(717,752)
Program, research, grants and support expenses	(394,914)	(744,729)
Depreciation and amortisation expense	(55,008)	(5,155)
Salaries and Wages	(2,131,497)	(2,423,459)
Finance costs	(64,695)	(90,073)
Other expenses	(295,767)	(96,438)
Total surplus/(deficit) for the period	280,453	(96,438)

For the complete Financial Statement visit heartkids.org.au

We love our Heart Beads

“Teliah has been on quite a journey this past year and receiving heart beads for each of her surgeries, procedures and follow ups helps to tell her story. Teliah’s beads are organised in order from her diagnosis during pregnancy and represent every medical event since. Each of these events is marked with a gorgeous bead and include the name we chose for our precious miracle baby when we first laid eyes on her, as well as her date of birth when her journey first began. It shows each of Teliah’s surgeries including her first open heart surgery at 10days old, in which we almost lost her. We will use the beads as Teliah becomes older to explain her Heart condition and all the things she has been through in her short life. Her beads will always be a symbol of how strong and brave she has been throughout it all. It is also a great way to explain to her brothers what happens to Teliah while she is in hospital.

They are only age 5 and 7 and love to explore her beads and count the days she’s spent in hospital, or the number of echoes she has had, and they are quite interested in what each bead means. Teliah’s string of heart beads will continue to grow with her and be a beautiful reminder of just how far she has come. Heart Beads are such an amazing initiative run by HeartKids that celebrate the journey of our miracle baby and little heart warrior. Heart Beads are one of the many blessings we receive from HeartKids and we will always be grateful for them. ”

Thanks, Kirsten Beek

Teliah 1 year

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.

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

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 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.



Michael 2 weeks



Izayvier's Story

No two stories are ever the same, every person's journey is different, and children born with congenital heart disease also have different stories. Some are born with small holes in their heart that close with no intervention while others are born with complex heart defects that require lifesaving operations. Unfortunately, the Newell family fall into the latter.

Young parents Logan and Angel like all expectant parents had hopes and dreams for their little family. All that changed in a heartbeat at their 18-week scan when little Azariah was diagnosed with Hypoplastic Left Heart Syndrome and an intact atrial septum.

Azariah had open heart surgery to open the intact atrial septum at only 10 minutes old. Sadly, he grew his wings at just 4 days old.

"Losing Azariah traumatised us and we struggled to cope. He was such a brave little fighter. He went through more in his short life than what some adults go through in their entire lives. Every day is hard, it absolutely broke us, but it also has made us stronger as parents."

Logan and Angel welcomed another baby boy in August last year. Unfortunately, little Izayvier was also diagnosed with various congenital heart defects at their pre-natal scan.

"Even though we had a better understanding of what to expect when Izayvier was born, we were so traumatised from losing Azariah that it was very hard going back to Westmead Hospital. The sound of beeping machines, the smell of the tapes used for the ventilator and feeding tubes triggered such anxiety and we both struggled. We didn't know if we'd be bringing a baby home."

Luckily after a 10-hour surgery at 3 days old and a pacemaker implanted at 10 days old and weeks of recovery, they were able to bring little Izayvier home.

It has come at an emotional and financial cost.

"Being a heart parent means a lifetime of hospital appointments and life never being the same. We have spent thousands of dollars on food and accommodation and all the other costs associated with a sick baby."

"We didn't know about HeartKids when we had Azariah and having had such amazing support with Izayvier we wished we had known. HeartKids have been there for us prenatally and during our hospital stay, always checking up on us and have helped us out financially so we could afford meals and accommodation allowing us to be close to Izayvier. Since we left hospital, they have also connected us with other heart families who understand our lives and provided further financial assistance as things have been tough with one income. This time around we have felt less alone and are forever grateful."

Angel, Azariah & Izayvier's Mum

P.S Little Izayvier is doing well and is a curious and happy little boy.

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