



HeartKids

**ANNUAL
IMPACT REPORT
2022**



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 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.

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"HeartKids has been instrumental in the support they offered us during our hospitalisation," said Alicia.

"I was introduced to HeartKids by the cardiac staff at Women's and Children's Hospital in Adelaide and quickly linked up with the HeartKids parents' Facebook group looking for support from families who have been in our situation. I reached out to Tania from HeartKids the night before we were due to fly to Melbourne, and she got back straight away, even at 9pm at night. She reassured me, provided me with a range of information and linked us with the Victorian team while we were in Melbourne. They provided us with support packages and financial aid. Since Piper has recovered, the team has introduced us to other families.

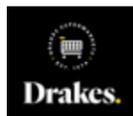
Piper and I do what we can to support HeartKids to this day through fundraising and sharing our story in order to help raise awareness of the amazing work that HeartKids does and secure funding into the future."

Alicia Littledyke Piper's Mum

THANK YOU

We couldn't do what we do without the unwavering support of our corporate and community partners, Trusts and Foundations, major and regular donors as well as the amazing support from our community.

Major Partners



Supporting Partners



Government Support

Commonwealth 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
City of Brisbane

Trusts & Foundations

Bank SA Foundation
Marian & EH Flack Trust
Edwards Lifesciences
The James & Jutta Lauf Foundation
UnLtd Foundation
The Lin Huddleston Charitable Foundation
McCusker Charitable Foundation
CAP
Commonwealth Bank Staff Community Fund
The Lyone Foundation
Tim Blair Foundation

Bequest

The estate of the late Elizabeth Mihic

Major Supporters & Gifts in Memory (\$5,000+)

QLD
Emily's Hope
AP Eagers Foundation Limited
NSW | ACT
VivCourt Trading
Dora Creek & District Workers Club
Terumo
IMB Foundation
Northern Beaches
Social Riders Club

Sofia's Battle
Heritage Bank – NSW Division
Arthur Stafford
Castle Hill RSL Group

SA | NT

Henschke Household
Katerina Iliopoulos
Westfield Local Heroes
Telethon SA Home Lottery
Sophie Kareta (Boffo Real Estate)

VIC | TAS

Bignell Household
Stannards Accountants and Advisors
Oz Hog Melbourne
Branded Burgers and Bar
Chicks for Charity Foundation
AFL Gamers
Shepparton Real Estate
Feel Better Box

WA

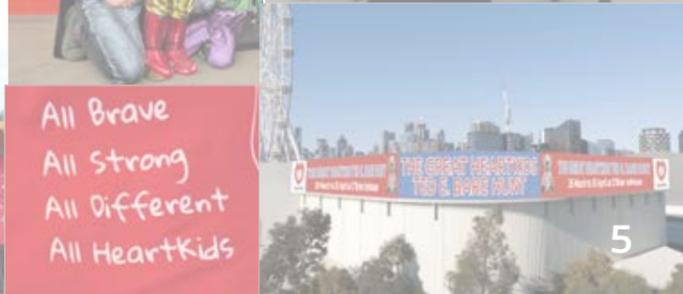
All Saints College
Lynn Yager
WA Charity Direct
Atlas CEA
Fennell Tyres International
Atlas Copco Power Technique Australia
Riding Free Brothers Motorcycle Club
TransAlta Energy Australia
Merrell Davis OAM

In-kind Supporters

Crown Entertainment Ltd
O'Brien Icehouse
Clayton Ute Lawyers
Roche
Melbourne Zoo
David Strassman
City of Melbourne
IFLY Melbourne

Media & Communications Partners

ARN
CocoGun
Fivegrid
Initiative Media
Kantar
Lightbulb
oOh!Media
Mobile Digital
Seven Network
Tonic Health Media
WriteAway
UnLtd



All Brave
All Strong
All Different
All HeartKids



CHAIRPERSON'S FOREWARD

On behalf of the Board of Directors of HeartKids Limited (HeartKids), we are pleased to present HeartKids' Impact Report for the year ending 30 June 2022.

I have been fortunate to join HeartKids as the new chairperson in April of this year after Jan McClelland AM, announced her intention to step down as Chair and a Director of HeartKids.

There is no doubt that 2021/2022 has been trying for all in Australia. COVID-19 has continued to impact not only HeartKids but all in our community and coupled with the rising cost of living there have been many challenges to overcome. There does however feel like there is light at the end of the tunnel.

Although our support staff continue to be in and out of the hospitals due to the various State COVID-19 restrictions, we continue to provide a high level of support to the families when they need it the most. Our fundraising and support events have largely returned to face-to-face, which has given not only staff but our at-risk community a reason to smile. As we move into a more dynamic state, we will continue to provide both on-line and face-to-face options for our community to engage in.

This year we continued to deliver the National Strategic Action Plan for Childhood Heart Disease – Beyond the Heart: Transforming Care (the Action Plan). The Action Plan team have been able to:

- develop the first draft of the Australian National Standards of Care for Childhood-onset Heart Disease
- deliver new consumer education resources and information to better meet the needs of our community;
- develop education modules for healthcare professionals;
- pilot an app to help young adults transition into adult care;
- streamlined the HeartKids Helpline providing more ways to connect with HeartKids.

We are grateful for the funding provided by the Commonwealth Department of Health that made these developments possible.

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

I would like to take this opportunity to thank retiring Chair, Jan McClelland for her tireless work, without which HeartKids would not be where it is today! Jan was instrumental in helping develop, achieve recognition of and secure Federal Government funding for HeartKids as the national charity delivering much-needed information, education, support, advocacy and research services for people impacted by congenital and acquired childhood heart disease across Australia amongst many more achievements during her 6 years as the inaugural chair of HeartKids Ltd.

I would also like to thank retired Board Director Lisa Selby for her many years of valuable service. Lisa still gives to HeartKids through her leadership of the HeartKids Research Committee.

Finally, on behalf of the whole HeartKids Board, we extend our sincerest thanks to all those who have contributed their time and resources to support our organisation and helped us achieve our purpose and goals this year and, in the years to come.

Elizabeth Foley
Chairperson



Lily 7 years

MESSAGE FROM THE CEO



Our community continues to amaze me. The warmth and support that you all spontaneously give to new parents of heart kids, to one another, to heart teens and heart adults is always amazing to see.

A true demonstration of the depth of human spirit and kindness, supporting each other in a remarkable way. The resilience shown is extraordinary and many within our community have risen to the challenge in what has been another hard year. Not only have you helped to support HeartKids so we can better support others, but you have shared your knowledge, hopes and needs with us to drive new program development. Thank you!

A year ago, I didn't think I would be writing again about the impact that COVID-19 has and continues to have on our community but what is encouraging for me, is to see that despite this our staff, communities, and families have adapted to the changes as we work toward establishing a new normal.

We will continue to provide hybrid service delivery with both on-line and face-to-face support available to support everyone, especially our rural and remote families. This will extend to our events and fundraising activities as we adapt and meet your needs.

As an organisation, HeartKids has grown stronger not only financially thanks to the generosity of our community and new corporate supporters like Supercheap Auto, but also in developing new services in areas such as Mental Health and Early Childhood Intervention, developing new support assets such as podcasts and translated information leaflets for people from non-English speaking backgrounds, increasing our presence in all Australian children's hospitals, as well as making huge strides in delivering the outcomes from the National Strategic Action Plan for Childhood Heart Disease, we could not have done it without your support.

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, finding new ways to deliver a wide range of leading-edge services to heart kids and families, engaging new sponsors, building new corporate partnerships, and piloting new programs.

I would like to thank the Board of HeartKids for their ongoing support, our wonderful community, corporate partners, trusts and foundations. Most importantly I would like to thank the amazing HeartKids staff who continue to innovate in an ever-changing world, always making sure that they deliver service excellence to the HeartKids community with great passion, dedication and care.

Fiona Ellis
CEO

OUR IMPACT

1,700



calls made to just check-in

876

families supported in hospital



2,000

FROM THE HEART
THE PODCAST



downloads on the podcast

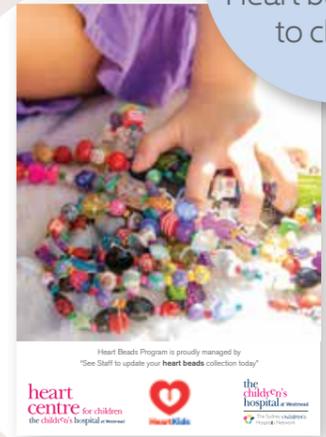
218

families provided financial assistance



Over 5,000

Heart beads given to children



1,400

Face to face support occasions



4,400

support occasions



MEET OUR DIRECTORS



Elizabeth Foley
Chairperson

Elizabeth Foley is a seasoned Non-Executive Director and CEO, with experience across a range of sectors, including financial services, digital innovation, health and medical research and professional services industries. Over the past ten years, Elizabeth has worked in the Australian health and medical research sector, five years as CEO and Managing Director of Research Australia, six years on the Board of the Population Health Research Network (PHRN), and three years creating the Digital Health Cooperative Research Centre (DHCRC).

Elizabeth has led a digital transformations of organisations resulting in increased in membership and services offered, and a dynamic turnaround in profitability.

Elizabeth is currently on the Board of the Australian National Research Organisation for Women's Safety (ANROWS) and Chair of the audit and risk committee. Elizabeth has exemplary formal qualifications, proven business acumen and brings stakeholder management credentials, particularly working with senior levels of government. Elizabeth is ambitious to see Australians who have congenital heart disease or who develop heart disease as children lead fulfilling and healthy lives.



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 of HeartKids, Chair of the Nominations and Remuneration Committee and a member of the Finance and Risk 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 AUSactive since 2018 and Chair of the Marine and Civil Maintenance Board 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

Beverley 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 with a focus on business transformation. Throughout her career, she has worked across State, Federal and Local Governments.

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 7 years and is committed to the development and growth of HeartKids Ltd. Beverley is also a chair of the Finance and Audit Committee.



Jared Brotherston
Director & Company Secretary

Jared has over 18 years' experience as a chairman, non-executive director and company secretary in both Australia and New Zealand across multiple industries. He is a Fellow of the Governance Institute of Australia and a Graduate of the Australian Institute of Company Directors.

A construction barrister by training, Jared has held company secretarial and senior 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 in Western Australia.



David Celermajer AM
Director

David Celermajer AO is the Scandrett Professor of Cardiology at The University of Sydney, Director of Adult Congenital Heart Services at the Royal Prince Alfred Hospital and Clinical Director at The Heart Research Institute.

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

Prof Celermajer has extensive experience as a Board director in the not-for-profit sector. He has been on the Board of HeartKids Australia since 2016. He was on the Board of the Menzies School of Health Research from 2009 to 2017 inc. He has served 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. He is currently Director of Research for Cardiology at RPA Hospital.



Rohan Geddes
Director

Rohan has been a Director of HeartKids since 2016 and currently sits on the Finance & Risk Committee and the Nominations & Remuneration Committee.

Rohan is a Partner at PricewaterhouseCoopers, where he leads the Payroll Advisory & Organisation practice. He has over 30 years' experience helping employers on workforce related matters, ranging from employment tax and regulatory obligations to HR transformation and effectiveness reviews. In addition, Rohan has served on profit for purpose boards across multiple industries including sports, arts, and commerce.

Rohan is a Heart Kid himself, having been born with Tetralogy of Fallot. He has a deep appreciation for the support and strength provided by parents of Heart kids and is grateful for the opportunity to contribute back to the HeartKids community as a way of recognising the support he has received.



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.



Ken Murphy

Director

Ken has over 25 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.)



Simone Wright

Director

Simone Wright (CPHR GAICD) has held Directorships with Pearson Australia Group and is an experienced Executive with a background in High Tech Manufacturing, Fast Moving Consumer Goods, Architecture, Financial Services, Publishing and Education sectors. She is the Chief Human Resources Officer for Victoria University while balancing her director career.

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



Lionel Henderson

Director

Lionel is an experienced Company Director, having been a Director or Company Secretary for several CSIRO joint ventures since 2004, and is currently a director of a number of food industry companies, a technology transfer consultant and a member of the Science Advisory Board for a synthetic biology company. He was a Director of Business Development & Commercial with CSIRO for 17 years, where he developed the framework for several research alliances and collaboration frameworks, including public – private partnerships, and he managed CSIRO’s involvement in multiple CRCs. Lionel managed the licensing for a range of CSIRO’s technologies domestically and internationally and was based in the US for most of 2018. He has also been a member and Chair of a number of external committees for CSIRO.

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 for over 30 years.

As the grandfather of a Heart Kid, Lionel is committed to the success of HeartKids Ltd.



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 Master 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.



Elsa van Wijk

Director

Elsa is an experienced and trusted adviser to Australian and international organisations and their boards. Her experience has been gained in the technology and innovation sectors, developing and delivering digital content and solutions to consumers and clients.

She has shaped, developed, and implemented strategy and organisational direction in multidisciplinary teams. Elsa engages and builds strong relationships with stakeholders to achieve organisational goals. Elsa has a child with CHD so is acutely aware of the journey and experiences of heart families. Elsa has joined the HeartKids Board to contribute to and achieve equitable access to support and allied health services and funding to all CHD patients and their families.



Ragnimarie 5 years

HIGHLIGHTS FROM OUR STRATEGIC PRIORITIES

At HeartKids, we aim to support the over 80,000 Australian children, teens, and adults affected by congenital or childhood-acquired heart disease (CHD), and their families. Our purpose is to help every child, teenager, and adult in Australia with CHD have a fighting chance to live a long, healthy, and fulfilling life. Below are just some of the highlights that we have achieved and continue to deliver on to meet our strategic priorities.



DELIVERING THE NATIONAL STRATEGIC ACTION PLAN FOR CHILDHOOD HEART DISEASE (ACTION PLAN)

The Action Plan is the first nationally coordinated effort to tackle Childhood Heart Disease and provides direction and guidance to transform care so that it is lifelong, holistic, person-centered, and family-centered

Proudly led by HeartKids, the implementation of the Action Plan is well underway with particular focus on:

Standards of Care

The last year has seen the publication of the First Draft of the Australian National Standards of Care for Childhood-onset heart disease followed by three months of public consultation on the Draft Standards. A review of public and stakeholder feedback was then undertaken and drafting of the Second Draft of the Standards is underway.

Education for Health Professionals

The HeartKids Education Portal project has seen a number of milestones achieved with the selection and set-up of a learning management system and the creation of working groups to advice on specific content for the education modules. The drafting of the first series of health professional CHD education modules on CHD and exercise is also underway.

Consumer Education and Communication

Following a consumer survey to ascertain the information gaps and resources required, HeartKids launched a number of new initiatives including:

- From The Heart Podcast with 20 episodes now available,
- Translation of key CHD fact sheets into six languages
- New print and digital resources including a mental health fact sheet for young people, a 16-page booking "Growing Up With Heart Condition: A Teenagers' Guide"
- New consumer videos that explore different educational messages based on the priority themes identified in consumer consultation including teen transition readiness, outlook and quality of life, parents' mental health, navigating new diagnoses, preparing for surgery, and managing CHD in adulthood



Georgia 4 months

- Co-production of a series of educational videos with the Murdoch Children's Research Institute (MCRI) focused on sharing patient and family experiences of paediatric heart failure
- Created a new platform to strengthen our connection with the priority population of teens and young people (Instagram: @youthzone_heartkids)

National HeartKids Helpline

Ongoing provision of HeartKids 1800 Helpline service continues to meet community demand, including the increased ability for the CHD community to access Helpline supports over Public Holidays as a call-back service, the launch of Webchat and SMS options for Helpline assistance to reach a wider audience within the CHD community. HeartKids has also piloted a CHD Directory which is a digital directory of health professionals, health care organisations and support networks and groups for people impacted by CHD.

Young Person Engagement

A number of initiatives have been underway to support this group including

- The pilot of UpBeat teen transition app
- HeartKids Aboriginal and Torres Strait Islander Teen Camp held on the Sunshine Coast in December 2021
 - Attended by 15 young Indigenous people from all over Australia including very remote communities
- HeartKids Day Out networking and education day for young people with heart conditions held in Tasmania and Canberra



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

SUPPORTING ON-GOING RESEARCH

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.

HeartKids has secured ongoing funding from the Commonwealth Department of Health to continue to deliver the Action Plan initiatives and projects until 2025.

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. This research is on-going with the research objectives focused on

- 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 Projects Supported Include:

CHAANZ Registry: An Australian Study of the Outcomes and Burden of Congenital Heart Disease

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

HeartKids commitment to this program of work is demonstrated by:

- cash support of \$520,000 from Jan 2020 to June 2022, and
- in-kind support, comprising active involvement in project design and implementation and measurement of outcomes; providing consumer input; assisting in raising awareness for the study recruitment and assisting with dissemination of the results to registry participants and the HeartKids community.

Congenital Heart Fitness Intervention Trial: CH-FIT

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

The study is based on a successful cohort spanning across five 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.

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.

HeartKids commitment to the above programs of work is demonstrated by:

- Provide consumer input for the grant;
- Provide continuing input as the project progresses;
- Assist in raising awareness for study recruitment; and
- Assist with dissemination of the results to the HeartKids community.

Research Priorities

HeartKids continues to collaborate with the CHD clinical and patient community to identify research priorities that deliver positive outcomes and insights to people with CHD. Currently, HeartKids is facilitating the development of the first Australian National Standards of Care for Childhood-onset Heart Disease (The Standards). 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. A working group was established to better inform the requirements that will form part of The Standards.

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. Consumers, being patients, families and carers, are central and integral to our identification and support of research with the greatest impact.



Anakin 2 years

SUPPORT AND INFORMATION

Providing our community with what they need when they need it

Support for and providing information to our community is at the core of what we do.

HeartKids provides evidence-based, up-to-date, and user-friendly information to families and adults impacted by congenital or childhood acquired heart disease. Coupled with the hands-on support from the team we aim to help reduce the feelings of isolation many families impacted by CHD experience.

Support

Providing support to our families is central to the HeartKids vision. We provide dedicated, quality support services to parents, carers, young people, adults, and Heart Angel (those who have passed away from CHD) families. Our aim is to provide guidance and support throughout the lifetime journey of our HeartKids community.

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

The past year has again proved challenging, our support teams have continued to manage hospital COVID-19 restrictions and the resulting reduction in face-to-face support contacts in hospital as well as reduced in-community support. These mandated COVID-19 restrictions resulted in continuous changes to our support provisions with more virtual, and/or phone support offered, our teams made over 1,700 support calls to check in with families.

Our Support team's dedication did not waver, they found new ways to assist parents when their child was diagnosed with congenital/acquired heart disease. They were able to pivot and develop new opportunities to provide ongoing support for families with infants and young children, young people, young adults, adults and bereaved parents and extended families with:

- Information – practical information and education opportunities
- 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, the Department of Human 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 works 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 HeartKid families, fostering ongoing peer support networks.
- Providing over 5000 heart beads to heart kids through most major children's hospitals across Australia representing their journey.

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



Benjamin 9 years

HeartKids Support also reaches regional and rural communities with several Regional Volunteer Coordinators committed to servicing these areas. In 2022, HeartKids also employed dedicated, externally funded Community Development Coordinators in Townsville, Mackay and Alice Springs.

Information and Resources

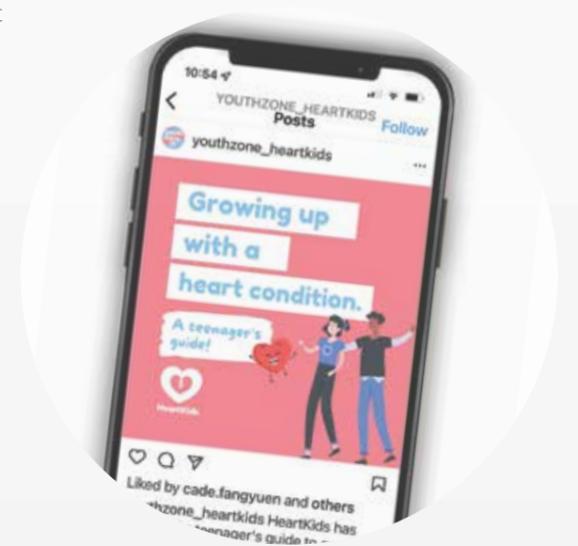
An extensive community survey was conducted to better understand the needs of the HeartKids community including information and resource gaps and services which were needed to best service heart kids and their families. This resulted in the launch of a podcast series, 'From the Heart', which explores stories of individuals and families impacted by congenital and childhood heart conditions and interviews with healthcare professionals on the topics that are important to our community. The hosts are Rachael Knowles and Sam Stolberg, two young Australians who live with CHD. In just 6 months these podcasts have been heard by over 2,000 people. New videos and factsheets have also been added to the resource library highlighting heart kid and family journeys, covering topics of mental health, teen transition, and the impact of CHD on the broader family. All have been well received. Information brochures about the services and resources available to the community have been distributed to the major children's hospitals.

Website and Social Media

The website continues to be the source of all information, news, events, stories, and fundraising campaigns for our community.

Social media is an integral way we communicate with our community. It 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.

We also launched a teen focused Instagram page (youthzone_heartkids) and Tic Toc account.





Lily 6 months

FUNDRAISING AND COMMUNITY EVENTS

Stronger Together

Community fundraising and events are a vital way that we raise funds and awareness to provide support programs across Australia. There are 3 major fundraising and awareness campaigns across the year and many localized fundraising and support events held across the States and Territories

HeartKids Sweetheart Day

HeartKids Sweetheart Day is a national awareness and fundraising campaign. The campaign is focused on Valentine's Day (International Congenital Heart Defect Awareness Day).

2022 saw HeartKids embark on our inaugural Sweetheart Giving Day, for 12 hours on February 14th every dollar donated to HeartKids was matched by our generous match donors – doubling every donation. It was a huge success with over \$280,000 raised on the day and a total of just over \$540,000 during the February Sweetheart Day campaign period. A big thank you to the major sponsor on the day – Supercheap Auto and all our community fundraisers.



To help raise awareness during the Sweetheart Day campaign we continued with a slightly revamped *Things can change in a heartbeat* awareness campaign.

The campaign was once again well received and an outstanding result of over \$3.3 million in pro bono media coverage was achieved thanks to our media partners led by UnLtd, Initiative and Write Away Communications.

HeartKids conducted pro-bono market research, through Kantar, to measure the impact of the awareness campaign. The campaign has managed to positively shift key metrics such as awareness and cause awareness, as well as showing that consumers are interested in donating to HeartKids and that HeartKids is growing as a charity that they feel is a cause that is important to Australians

In addition to this, we've also seen significant year-on-year growth for HeartKids, demonstrating that HeartKids is growing over time.



Hero For HeartKids Day

Friday 17 June was our Be a Hero for HeartKids Day, our national campaign encouraged businesses, schools and the community to dress up as superheroes and raise funds and awareness for HeartKids.

With COVID restrictions easing, we saw renewed enthusiasm amongst those getting involved with many sightings of superheroes across Australia. A total of \$480,000 was raised.

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 very special mention for our ongoing partner Drakes Supermarkets who contributed over \$180,000 to the campaign. A special thanks to our new corporate partner Supercheap Auto whose staff and retail outlets put their heart and soul into Hero for HeartKids Day in 2022.



HeartKids Two Feet & A Heartbeat Charity Walk

Despite this community walk being impacted by Covid-19 restrictions, 3,300 participants raised close to \$410,000. They all walked (whether around their neighbourhood or at an organized event) 4kms, representing the four lives lost to CHD each week 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 and dresses in red, blue, or white creating a powerful visual effect and community vibe.

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

Community Events

The State Support and Fundraising Teams were instrumental in organising community events over 2022. These have been both on-line (morning teas, Q&A sessions, adult Zoom catchups) to more recently face-to-face events including Zoo sleepovers, hospital and in-community morning teas and lunches, trivia nights, teen day outs, strike bowling, zip-lining and many more activities with many more planned in the coming year.



GOVERNANCE AND MANAGING RISK

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

The role of the HeartKids Limited Board is to ensure the development and 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 strategic direction;
- approving and monitoring financial performance;
- recruitment of the CEO and setting executive remuneration;
- ensuring the establishment and ongoing review of policies and procedures;
- establishing and monitoring the achievement of organisational goals;
- ensuring the integrity of internal controls 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;
- 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.

William 6 weeks

FINANCIALS



Myles 18 months

FINANCIAL REPORT AT A GLANCE

Statement of Profit or Loss and Other Comprehensive Income For the Year Ended 30 June 2022

	2022 \$	2021 \$
Revenue	4,896,982	4,335,483
Other income	80,066	547,113
Fundraising expenses	(559,053)	(582,336)
Program, research, grants and support expenses	(429,589)	(930,678)
Depreciation and amortisation expense	(141,667)	(105,669)
Salaries and Wages	(3,036,899)	(2,684,135)
Finance costs	(187,794)	(123,180)
Other expenses	(315,096)	(286,851)
Total comprehensive surplus for the year	306,950	169,747

For more information, please refer to our financial statements.



Emerson 2 months



Thank you

2022 saw our community rally and come together to support HeartKids. 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.

We look forward to working with Australian, state and territory governments, clinicians, researchers, corporate partners, heart kids, heart teens and adults, heart angel families and the broader CHD community as we strive to make a real and lasting impact for everyone in the Congenital Heart Disease (CHD) community.

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