



HeartKids FY24 Impact Report

Champions of the Heart – Making a lifelong impact for children, teens, adults and their families navigating childhood-onset heart disease.



Strong Hearts Strong Mob by Paul Constable Calcott



Acknowledgement

HeartKids acknowledges the Traditional Owners of the land on which we live and work. We acknowledge the continuing connections to land, sea, waters, and skies. HeartKids treads lightly on Country and works to collaborate with and support Aboriginal and Torres Strait Islander people, families and communities impacted by childhood-onset heart disease (CoHD) including rheumatic heart disease (RHD). We pay respects to all Elders past and present and thank the Aboriginal and Torres Strait Islander people who contributed to this document.

HeartKids recognises the imperative for systemic changes to improve service accessibility and culturally responsive care. Aligned with this vision, we are dedicated to developing and implementing our first Reconciliation Action Plan (RAP) over the next 12 months. This RAP will be instrumental in guiding us on our reconciliation journey, fostering meaningful engagement and collaboration and strengthening our presence within Aboriginal and Torres Strait Islander communities across Australia.

Strong Hearts Strong Mob

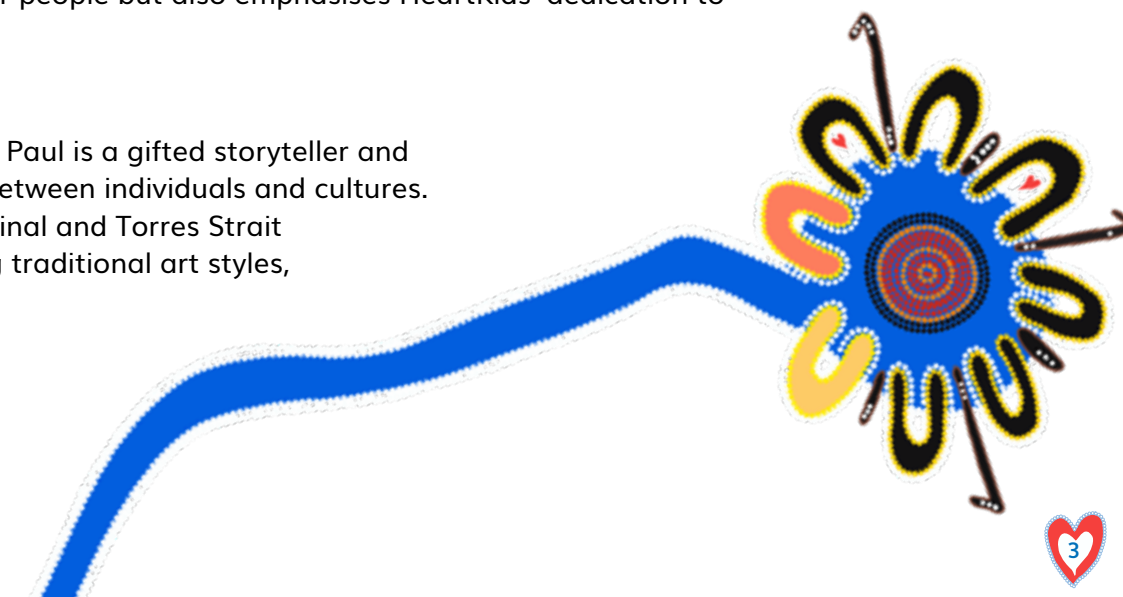
Strong Hearts Strong Mob reflects the diverse communities and cultures of Aboriginal and Torres Strait Islander people. The many nations are represented using colours and symbols, saltwater people in the blues and greens, mountain, urban and desert people in the browns and yellows, river people in the blue, rainforest people in the green.

Central to the piece is the HeartKids logo and is reflected across the piece to demonstrate our links and relationships with communities across Australia. The horseshoe symbols and circles are significant to many Aboriginal cultures as they represent the marks we leave in the sand when we sit for gatherings and the many people in our reach and aim to meet. The circles represent HeartKids joining with communities in various settings to have discussions about heart disease and share the many ways in which we provide support. This artwork not only highlights the rich cultural heritage of Aboriginal and Torres Strait Islander people but also emphasises HeartKids' dedication to fostering strong, supportive communities across Australia.

About the Artist - Paul Constable Calcott

Paul Constable Calcott is a Wiradjuri artist living on Gubbi Gubbi Country. Paul is a gifted storyteller and through his artwork provides a personal connection and mutual respect between individuals and cultures. Paul is an honoured member of the local community who supports Aboriginal and Torres Strait Islander artists with disability to connect to Community and culture. Using traditional art styles, Paul champions resilience via yarning and sharing stories.

Aboriginal and Torres Strait Islander people are warned this document may contain images and names of people who have passed.



Contents

About HeartKids.....5

Chair/CEO Introduction.....5

Our Impact at a Glance.....7

FY24 Strategic Overview8

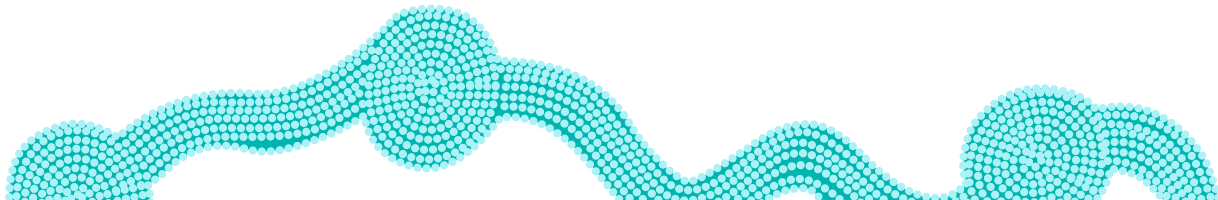
Expanding the Reach of Our Services and Advocacy.....9

Leading the way in CoHD support, education, and information.....12

Creating Impact in Priority Communities.....18

Transforming Lives: The Impact of Our Partners and Supporters.....22

Thank You.....28



About HeartKids

For over 40 years, HeartKids has been the leading voice for Australians impacted by childhood-onset heart disease (CoHD), with a focus on congenital heart disease and more recently inclusive of rheumatic heart disease (RHD). Our unwavering dedication and community support makes a lifelong impact on those navigating CoHD. We champion the CoHD community, fighting for more lives well lived and ensuring no one feels alone. With an estimated 250,000 Australians impacted, including nearly 6,400 with RHD in regional and remote areas, HeartKids plays a critical role in providing support, resources, and advocacy to children, teens, adults and their families.

Chair/CEO Introduction



Marcus Sandmann
CEO



Elizabeth Foley
Chair

Our strategic priorities in FY24 focused on expanding our services, strengthening our advocacy efforts pushing for consistency of care for all people impacted by CoHD, and diversifying our fundraising avenues to meet the growing needs of the CoHD community. With these guiding principles, HeartKids has continued to forge partnerships and pursue initiatives that drive meaningful, lasting change.

Through **7,495** support occasions, we delivered compassionate care to children, adults, and their families navigating complex journeys, with a special focus on reaching those in regional and remote areas. Our Community Support Coordinators, many with lived experiences of navigating CoHD, have been central to this work, offering emotional and practical care at key milestones and bridging the crucial gap between hospital and community support.

This year, we've also prioritised digital accessibility, creating new ways for teens, adults and their families to access information, resources, and support. Our newly launched online resource library offers over 200 resources including podcasts, videos series and fact sheets to support people at all life stages navigating CoHD. Additionally, our HeartKids Helpline, through phone and webchat, provides essential guidance for individuals and families nationwide, enhancing our role as a reliable source of support outside clinical settings.

A significant milestone this year was the publication and launch of the Australian National Standards of Care for Childhood-onset Heart Disease, supported by HeartKids. The Standards of Care were developed in collaboration with over 130 health professionals and individuals with lived experience, and as a

world-first are setting a new benchmark for quality care in Australia. This advocacy-driven project exemplifies our commitment to championing equitable and best practice care for all Australians living with CoHD.

As we move forward, we reflect with gratitude on the leadership of our former CEO, Lesley Jordan, whose dedication helped shape HeartKids into the impactful organisation it is today. We thank Lesley for her service and wish her all the best in her future endeavours. We also thank directors who retired from the board during the year, including Elle Pendrick, Beverley Barber, Matthew Tognini, and Prof David Celemajer, for their untiring efforts. We also acknowledge Deputy Chair, Rohan Geddes, for stepping into the role of Chair for three months while the Chair was on extended leave.

Looking to FY25, our focus remains on advancing our strategic priorities, building sustainable partnerships, and ensuring that every person impacted by CoHD has access to the support they need.

To our donors, volunteers, partners, board and staff—thank you for standing with us. Together, we are making a lasting difference, fostering a future where all individuals and families impacted by CoHD continue to thrive.

Our Impact at a Glance

7,495 Total Support Occasions

5,669 parents & carers

549 children

2,416 families with infants

219 adults

1,254 regional families

314 siblings

1,024 teenagers

79 bereaved families

Outpatient Clinic: 954 families supported

Practical Support: 278 vouchers provided

Antenatal Support: 154 families supported

Helpline Requests: 251 contacts made

Resources & Digital Engagement

80 new evidence-based written materials available and promoted including fact sheets, Easy-Read documents, videos, animations, and podcasts crafted for children, parents, teens, and adults impacted by CoHD.

116 attendees across Teen Camps in Victoria, Queensland, Perth, and Sydney

More than 100,000 views, listens or downloads across all resources

5,325 podcast downloads for From the Heart, fostering discussions on key topics around CoHD

23 learning modules released on our new Health Professional education platform

377 Educational Packs distributed

New online community HeartKids Connect established

227 Care Bags distributed, providing comfort and essential information to families.

Awareness raised about HeartKids and CoHD through 1223 total media pieces, with an estimated 87.5 million views

343 Heart Beads distributed, celebrating important milestones in the journeys of children and families.

FY24 Strategic Overview

In FY24, our strategic priorities centred on expanding our reach and enhancing our services to meet the evolving needs of our community, solidifying our role as a trusted leader in the provision of information and education on CoHD.

Through our FY24 strategic priorities, HeartKids continued to serve as a vital source of support and advocacy for children, teenagers, adults and their families navigating the complexities of CoHD.

- **Strategic Priority 1:** Expand our reach and services, and opportunities for advocacy and research
- **Strategic Priority 2:** Become the trusted leader in the provision of services, information, and education on CoHD in Australia
- **Strategic Priority 3:** Grow the HeartKids impact in our priority communities
- **Strategic Priority 4:** Strengthen, grow, and diversify fundraising and revenue sources
- **Strategic Priority 5:** Improve the quality and transparency of reporting, compliance, and risk management across the organisation
- **Strategic Priority 6:** Develop an agile, adaptive, and innovative workforce

This year, our Executive and Board developed the HeartKids Strategic Plan 2024-2027. HeartKids Strategic Plan 2024-2027 represents the vision of the Board to be recognised as the leading advocate and service provider for those impacted by CoHD in Australia. The plan ensures that as an organisation we are all clear on where we are headed, what we need to do and how we will know when we have achieved our goals. Looking ahead, we are committed to advancing these priorities, with a focus on expanding our digital presence and fostering deeper connections with our community to ensure sustained growth and impact. We look forward to reporting on our progress against these new Strategic Priorities in FY25.

1. **Future Support Model (For Life Model)**
2. **Digital Transformation**
3. **Productive Stakeholder Relations**
4. **Brand Impact**
5. **Future Funds**



Expanding the Reach of Our Services and Advocacy

HeartKids advocates for equitable, high-quality care for all families impacted by childhood-onset heart disease (CoHD), regardless of location or circumstance. In FY24, our advocacy efforts achieved significant milestones, laying the groundwork for broader systemic changes in healthcare for CoHD across Australia.

HeartKids Advocacy Priorities

As a leading consumer health advocacy organisation, HeartKids supports patients and families by advocating to Australian, State, and Territory Governments, health networks, and other agencies involved in the CoHD journey.

To date, HeartKids has achieved:

- Support from both South Australian and Western Australian Governments
- The National Strategic Action Plan for Childhood Heart Disease funded by the Australian Government with key initiatives currently being implemented including the Australian National Standards of Care for Childhood-onset Heart Disease.
- Advocacy for equitable access to government assistance and support for CoHD patients and families.

Our National Advocacy Strategy focuses on raising awareness, securing funding, and spotlighting the lived experiences of those affected by CoHD. Current advocacy priorities include:

- Access to support funding
- Access to social, psychological, and allied health support
- Bereavement support
- Transition from paediatric to adult care
- Expanding our regional support through both in-person services and digital resources.
- Collaborating with healthcare providers and Aboriginal Community Controlled Organisations to support efforts to reduce the impact of ARF and RHD.

Through strategic partnerships, we delivered educational programs and support for individuals impacted by CoHD across all states and territories, including initiatives like the HeartKids Health Professional Education Platform (learn.heartkids.org.au). This platform features 23 online, evidence-based CoHD education modules and 17 supplementary learning materials, all aligned with the CoHD Standards of Care. With over 800 course enrolments across more than 30 specialties—including GPs, cardiologists, paediatricians, allied health, and nurses—this platform is instrumental in equipping healthcare providers to deliver informed care.



Highlight: Launch of the Australian National Standards of Care for Childhood-Onset Heart Disease

On February 7, 2024, a landmark achievement for Australians impacted by CoHD was realised with the launch of the Australian National Standards of Care for Childhood-Onset Heart Disease, 1st Edition (CoHD Standards). With many of the CoHD health professional community, people impacted by CoHD and MPs/Senators in attendance, The Hon Mark Butler MP, Minister for Health and Aged Care, officially launched these standards at Parliament House in Canberra, representing a significant advancement in the care and support for the CoHD community.

HeartKids played a vital role in the development of the CoHD Standards as project coordinators, advocating for the needs of the CoHD community throughout the process. In conjunction with the full CoHD Standards, a consumer version was launched, along with translations into ten languages based on the prevalence of language groups in Australia. This ensures that critical information is accessible to a diverse audience, enhancing the support available for all families navigating this condition.

These standards are grounded in the lead principle of living well, recognising that many families manage this condition throughout their lives. Having clarity around the best standards of care and what to expect on this lifelong journey can alleviate significant stress.

HeartKids is proud to lead the advocacy and support for children, teens, and adults affected by CoHD, and these new Standards of Care mark a crucial step forward in improving health outcomes for over 250,000 Australians living with this condition.

Since publication in 2024, the CoHD Standards have been viewed over 3,500 times via the [CoHD Standards website](#). Multiple local and international conference presentations have been made in response to requests for briefing about and presentation of the CoHD Standards.



HeartKids and Murdoch Children’s Research Institute: A Health Alliance Partnership

In FY24, HeartKids and the Murdoch Children’s Research Institute (MCRI) made significant strides in bridging gaps between science, healthcare and patient advocacy for those living with childhood-onset heart disease (CoHD). Our Research Collaboration Agreement, established in 2023 as part of the Heart Failure Flagship project, focuses on improving lives through impactful research and incorporating lived-experience insights.

A key achievement this year was the launch of the Wadja Health Clinic video, a resource to support Aboriginal and Torres Strait Islander families at the Royal Children’s Hospital. This project is one of many where HeartKids has helped amplify patient voices and support needs, with HeartKids’ Tracy Stanley, a member of MCRI’s Patient Advocacy Group (PAG), offering her lived-experience insights to advocate for including patient perspectives in research and healthcare.

HeartKids further strengthened its collaborative role through a keynote address at MCRI’s Annual General Meeting and MCRI team members, Professors Enzo Porrello and Rob Weintraub, represented MCRI on the CoHD Standards working group. HeartKids also supported MCRI’s Heart Foundation Catalyst Grant application, highlighting our joint commitment to connecting research and advocacy for real-world impact on CoHD patients and families.

Our Health Alliance Partners

HeartKids collaborates with a range of valued partners across the healthcare sector, ensuring greater support and care for those impacted by CoHD.



Wadja Walkthrough Video



In collaboration with the Murdoch Children’s Research Institute, HeartKids launched the Wadja Walkthrough Video to support Aboriginal and Torres Strait Islander families visiting the Royal Children’s Hospital (RCH) in Melbourne for cardiac treatment. Guided by Aunty Netty from the Wadja Aboriginal Family Place, this culturally sensitive video familiarises families with the hospital, easing their experience, particularly for those new to Naarm (Melbourne).

With over 10,000 views online, this resource is helping families feel welcome and prepared.



Leading the way in CoHD support, education, and information

Childhood-onset heart disease (CoHD) is often a lifelong journey, and so is HeartKids’ support. Through our ‘For Life’ Model of Support, our teams—many with lived experiences navigating CoHD—provide emotional and practical care to children, adults and their families facing hospitalisations and long-term needs. Our services are tailored to key life milestones—from diagnosis through schooling, teenage years, and adulthood—ensuring our CoHD community receives expert guidance at every stage.

In FY24, HeartKids focused on enhancing our support for the CoHD community, adapting our programs to meet evolving needs and expanding our reach across Australia, particularly in regional areas. We strengthened our presence in hospitals and collaborated with healthcare professionals and over 30 organisations, including Aboriginal Community Controlled Organisations, to deliver culturally relevant care. Last year, we facilitated 7,495 support occasions, with 5,669 instances of support for parents and carers. In addition to in-person care, we provide a range of digital resources through our new website and online resource library, featuring podcasts, videos, and factsheets tailored to every life stage. Our HeartKids Helpline offers emotional and practical assistance, bridging the divide between clinical care and community needs.

HeartKids continues to evolve our service delivery, combining online and face-to-face support to cater to all families, especially those in rural and remote areas. Our community, partners, and stakeholders provide vital support, offering meal vouchers, grocery assistance, and shopping discounts to ease the burdens families face. Our goal is to enhance access to services across Australia while providing comprehensive care at every stage—from early childhood intervention to adult cardiac care and palliative support. Together, we ensure that HeartKids is there for families every step of the way.



HeartKids Model of Support

Individuals and families with a diagnosis of CoHD often face complex and challenging healthcare journeys. HeartKids is a lifelong champion for all impacted by CoHD, providing comprehensive and experienced care through key life milestones.

By delivering in person and online support and education at strategic milestones across a person’s life-long CoHD journey, and their families.

- Diagnosis
- Prenatal
- Early Childhood
- Childhood
- Teen / Young Adults
- Adults
- Parents / Carers & Siblings
- Bereaved Families

Note: Most cases of CoHD are diagnosed in utero, infancy or early childhood, but diagnosis can also happen later in life.

Providing support services where and when needed.

- All major Children’s Hospitals & Clinics
- In the Community
- Regional, rural & remote locations
- Priority Populations
- Aboriginal & Torres Strait Islander communities
- In person & online

Building resilience and capacity to manage their CoHD journey through...

- In-Person Support
- Referral Networks
- Mental Health & Wellbeing
- Peer to Peer connection
- Early Childhood Intervention
- Educational Resources
- Information Sessions
- Digital & Social media engagement

Empowering families living with CoHD to overcome the barriers of this chronic condition, equipping them with the necessary tools and support to live their best life.



New Early Childhood Intervention Programs: Better Beginnings and Better Starts

Launched in FY24, the Better Beginnings & Better Starts programs provide essential early intervention and guidance for parents of young children with CoHD. Focused on both pre-school and early school years, these programs support key developmental milestones, creating a strong foundation for the youngest members of our community. Beyond developmental progress, these Early Childhood Intervention (ECI) programs offer families a sense of connection and community. We gratefully acknowledge the support of the SA Health Department, the Walker Family and Kiwanis. The ongoing support of these partners over many years and investment has resulted in the development of programs such as these.



Our People: Amy's Community Support Impact

Since joining HeartKids in 2011, Amy has become an integral source of support for families navigating CoHD.

As a Community Support Coordinator based in Melbourne, moments from the Royal Children's Hospital, she is part of a dedicated team that offers compassionate, personalised guidance to families navigating long and challenging hospital stays.

Amy's role centres on delivering tailored support, tuned to each family's unique needs. "Support is really individual for each family that comes through the hospital," Amy shares. "It's based on their personal circumstances—whether they're local or have travelled from interstate, which often means helping with essentials like accommodation."

This approach is at the heart of what HeartKids' Community Support Coordinators do nationwide, meeting families where they are, with care that's practical, empathetic, and genuinely impactful. For families staying in the hospital for extended periods, Amy's role often becomes a steady source of belonging and connection. "For families here for months or even years, you get to know them and their children like they're part of your own family."

Amy's personal experience as a heart mum, like that of many of our Support Coordinators with their own lived experiences navigating CoHD, offers invaluable insight into the emotional challenges families face.

"Every day, I have moments when I recognise exactly what a parent might be feeling," she reflects. Amy recalls her own time in the hospital, remembering the isolation she felt until connecting with other HeartKids families. "Knowing you're not alone, that there's someone else who understands—that's so powerful," she says. This empathy is a guiding principle for HeartKids' team of support coordinators, all of whom are deeply committed to standing by families when they need it most.



Stories of our support



Phoebe’s Story

Phoebe’s journey with CoHD began at birth. Born prematurely, she was diagnosed with tracheoesophageal fistula, oesophageal atresia, duodenal atresia, and Tetralogy of Fallot – a combination of four congenital heart defects. Phoebe’s mother, Emily, recalls the early months as a blur: “She was covered in tubes. I was scared I’d lose her so many times, but I could never imagine life without her.”

Through HeartKids, Emily connected with not only support but also other families facing similar challenges, finding community in a difficult time. As Phoebe continues to grow, Emily feels reassured knowing that HeartKids will be there for every stage, from childhood support to teen camps.

“The HeartKids team and the resources have been invaluable. It’s been a great space to learn, be empowered to ask questions and understand what my daughter and other families are going through. I have especially loved the way they just know what to say or how to listen when you just need that ear or shoulder to cry on, it always comes from a place of compassion, empathy and understanding. I’m a solo mum by choice so having the support and community is really special to me. It takes strength for them to show up for us when we are at our worst.”

Now at 20 months old, Phoebe’s resilience shines as she thrives outside of the hospital.

“She had a tricky start so she is on her own pathway forward and that’s absolutely ok with me. She is ticking off some big milestones and I am just so lucky to have her.”

Luca’s Story

When Luca’s parents received the diagnosis of childhood-onset heart disease (CoHD) during a routine antenatal appointment, they were plunged into a world of uncertainty. Their first support arrived through the **HeartKids 1800 Helpline** and a referral on to Joanna Harb, HeartKids’ Sydney Community Support Coordinator, Luca’s dad felt immediate relief knowing someone who understood their situation was there to support them. Joanna, herself a parent with lived experience of CoHD, was able to provide comfort and knowledge that made the daunting journey feel more manageable.

Their first meeting over coffee was a powerful connection point. “HeartKids provided us the comfort that we were not alone in this journey, not only as parents, but also for Luca too,” Luca’s dad recalls. Joanna’s guidance became invaluable, especially after Luca was born and underwent his first surgery. Joanna visited the family regularly in the PICU, helping them navigate the emotional rollercoaster of intensive care.

As Luca’s journey continued on the hospital ward, Joanna’s presence remained constant. She offered practical advice and a listening ear, offering strategies and guidance to support managing and navigating hospital stays.

Now at home, Luca’s parents keep Joanna updated on his progress as he continues to thrive, hitting all his milestones.

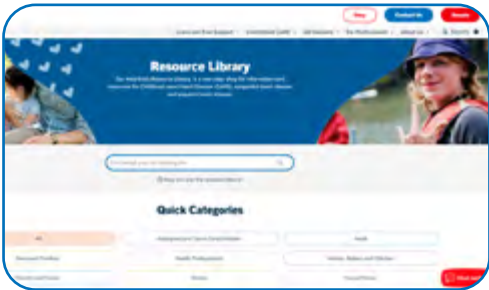
“HeartKids will have a lasting impact on our family forever. They were there during our toughest times and stuck with us to see our thriving 8-month-old Luca kicking all his milestones.”



HeartKids Resources and Digital Support Expansion

In FY24, HeartKids launched a revamped website and digital resource library, making CoHD information readily available to people navigating CoHD across Australia. Designed with accessibility and user experience in mind, these resources provide vital information at every stage of the CoHD journey, from initial diagnosis to adulthood.

Highlights:



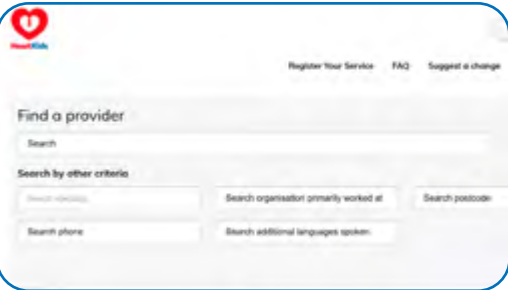
HeartKids Resource Library

Our comprehensive online library features over 200 resources, including factsheets, Easy Read resources, videos, podcasts, and guides tailored for different life stages.



Educational Videos

Our new video series’, CoHD Explained and Real Talk, have reached a combined viewership of 80,000, offering families engaging, digestible information on topics like health management, exercise, and transitioning to adulthood.



CoHD Directory

Our national directory connects families with healthcare providers and local peer groups specialised in CoHD support, serving 1,023 users this year.

Highlight: HeartKids From the Heart Podcast



The *From the Heart* podcast delivers important conversations for anyone impacted by childhood-onset heart disease (CoHD). Covering key topics like navigating a new diagnosis, mental health, and the realities of open-heart surgery, this series offers real support and insights from both CoHD patients and healthcare professionals. Hosted by Rachael Knowles, Sami Glastonbury, and Tahnee Jash—three Australians with personal experience of CoHD—the podcast creates a supportive space for meaningful discussions. This year, *From the Heart* reached 5,325 streams across platforms, deepening connections within the CoHD community and providing essential information and solidarity.



Creating Impact in Priority Communities

This year, HeartKids placed a renewed focus on reaching people in regional and remote communities, as well as collaborating to provide support and care for Aboriginal and Torres Strait Islander communities impacted by rheumatic heart disease (RHD). By delivering culturally responsive and regionally tailored support, we aim to make our programs accessible to families who may otherwise face barriers to healthcare.

Our Regional Support

HeartKids has seven part-time Community Support Coordinators in ACT, WA, SA, NT, QLD, and VIC, each providing critical support equivalent to three days per week in regional areas. These coordinators bridge the gap between clinical and community care, particularly in regions with limited healthcare access, collaborating with hospitals and over 30 organisations, including Aboriginal-controlled groups, to deliver culturally sensitive support. Our outreach extends to remote clinics, such as those in Geraldton and Albany, WA, in partnership with Perth Children’s Hospital. In the first half of 2024 alone, we provided 84 support occasions in regions like the Kimberley, demonstrating the strong demand for accessible services. With increased support, we aim to expand these essential services, reaching more families in rural and remote areas across Australia.

Aboriginal and Torres Strait Islander Outreach and RHD Support Collaboration

HeartKids is dedicated to supporting Aboriginal and Torres Strait Islander people, families, and communities impacted by CoHD, including ARF and RHD.

In collaboration with Aboriginal and Torres Strait Islander healthcare providers and Community Controlled organisations, we aim to enhance care delivery and tackle the unique challenges of remote communities, promoting self-determination and social and emotional wellbeing. In FY24 we appointed an Aboriginal and Torres Strait Islander Engagement Manager who has established strong partnerships with organisations and individuals, including Children’s Ground and the Palm Island Community Company, formalised through Memorandums of Understanding (MOUs). We currently have two projects underway to produce develop community-led resources for the prevention and treatment of RHD.

A highlight of our regional initiatives was the Aboriginal and Torres Strait Islander Teen Camp held in Sydney. This four-day camp provided a culturally safe environment for 34 teens to connect, share experiences, and receive health education. Led by cultural advisors and supported by First Nations volunteers, the camp empowered participants to take charge of their health while celebrating their identities.



Teen and Young Adult Empowerment

HeartKids recognises that the journey with CoHD extends into adolescence and adulthood. Our Teen and Young Adult Programs are designed to provide ongoing support as young people face unique challenges, from transitioning to adult healthcare to managing CoHD in their daily lives.

FY24 Highlights:

- **Teen Camps:** 116 attendees across our camps in Victoria, Queensland, Perth, and Sydney this year, participants enjoyed a blend of outdoor activities, educational sessions, and social events designed to foster self-confidence and independence.
- **New webinars and Connect and Share virtual events launched:** Over 80 young adults engaged in Real Hearts, Real Talk webinar, the first of four webinars being delivered through FY24/25 for adults and teenagers.
- **HeartKids Connect online community:** Developed throughout FY24 and launched in November 2024, this new social space offers a dedicated, accessible platform where individuals and families can connect, access essential resources, receive peer support, and find information tailored to their journey with CoHD.
- **Resources available for teens on our new website:** In FY In FY24, HeartKids launched a dedicated resource space for Heart Teens, providing young people with access to tools, resources, and events tailored to their needs. Young people can find guides on growing up with a heart condition, support for healthcare systems transitions and HeartKids UpBeat App.



Highlight: New Webinar Series Launches with Real Hearts, Real Talk



In June 2024, HeartKids hosted *Real Hearts, Real Talk*, a virtual event uniting young adults (18-35) with congenital and childhood-acquired heart conditions from across Australia. This impactful evening featured expert insights from A/Prof Dominica Zentner, cardiologist and leader of the Cardiac Pregnancy Clinic at Royal Melbourne Hospital; Dr. Charlotte Verrall, neuropsychologist at Sydney’s Royal Prince Alfred and Sydney Children’s Hospital; Elle Pendrick, founder of Adulting Well; Amber Adamson, Acting Adult Congenital Heart Disease Clinical Nurse Consultant at The Prince Charles Hospital; and Dr. Derek Tran, exercise physiologist at the University of Sydney and Royal Prince Alfred Hospital. This was the first of three webinars supporting the CoHD community throughout 2024-2025, creating a supportive space for shared learning, peer connections, and Q&A.

Highlight: HeartKids Teen Camps



In 2023/24, HeartKids hosted Teen Camps in multiple locations, including the Sunshine Coast and Victoria, bringing together heart teens, volunteers, and HeartKids staff for enriching experiences. These camps welcomed teens aged 13-17 from diverse backgrounds, including those from remote areas and Aboriginal and Torres Strait Islander communities.

The camps provided invaluable opportunities for young people living with childhood-onset heart disease (CoHD) to foster connections, enhance health management skills, and, most importantly, have fun in a safe and supportive environment. Each camp featured a mix of returning campers and new faces, engaging in exciting activities like high ropes courses, visits to local attractions, drumming circles, campfires, and trivia nights. Informative sessions, including a health panel led by experienced nurses and HeartKids' Transition Program Coordinator, offered insights into managing their health as they grow.



A notable camp, the Aboriginal and Torres Strait Islander Teen Camp, was held in Sydney in January 2024, bringing together 34 teens from regional Australia. This four-night camp emphasised health education, empowerment, and connection, led by Teen Camp Coordinators Michelle Chee and Amy Heafield. Teens were guided by a cultural advisor and supported by First Nations volunteers, ensuring cultural safety while integrating activities that celebrated their identities. Medical oversight, provided by Registered Nurse and HeartKids Teen and Young Adult Program Coordinator Margot Pitman, ensured comprehensive support and healthcare advice. Margot reflected how one camper from the Aboriginal and Torres Strait Islander Teen Camp shared how the experience empowered her to manage her health: "It was empowering—she learned to listen to her body and take charge of her wellbeing." The camp culminated in a visit from rugby star Kennedy Cherrington, who inspired campers by sharing her journey and proving that medical challenges needn't limit their goals.



Throughout all camps, the true highlight is the friendships formed, as teens connect with peers who understand their unique experiences. For many, it's a chance to reconnect with friends from previous camps or to meet new ones. Despite living miles apart, campers often maintain these connections, offering each other essential support as they navigate the challenges of growing up with CoHD.

HeartKids Teen Camps are open to all heart teens aged 13-17. Through these events, we foster ongoing healthcare relationships, empowering teens to manage their health within their communities and envision brighter futures. To learn more about upcoming camps, visit HeartKids Teen Camps.



Transforming Lives: The Impact of Our Partners and Supporters

HeartKids' mission to support families impacted by childhood-onset heart disease (CoHD) is made possible through the dedication and generosity of our community. From corporate partnerships to individual donors and our incredible volunteers, every contribution fuels our work, enabling us to reach more families and provide vital resources across Australia. This year, our supporters' commitment has helped transform lives and expanded our capacity to deliver impactful care where it's needed most. We are proud to showcase the incredible impact of their efforts and look forward to deepening these connections as we continue our journey.

National Campaign Highlights

- **Sweetheart Day:** HeartKids Sweetheart Day is a fundraising and awareness campaign that takes place annually to support people impacted by CoHD. This year the campaign ran from January through February with a special focus on awareness on the 14th of February, International Congenital Heart Defect Awareness Day.



- **HeartKids Gala Ball, WA:** The HeartKids Gala Ball is a night to celebrate the achievements of our organisation and the combined efforts of our Western Australian community to support families impacted by CoHD. With over 700 guests attending, the Gala Ball was an unforgettable evening with gourmet dining, premier entertainment, live auctions, raffles, and a live band that kept the celebration going until late into the night!

- **Hero for HeartKids:** Hero for HeartKids Day asks businesses, schools and the broader public to dress up as superheroes to raise awareness for CHD and raise money for HeartKids. This year over 1,200 fundraisers nationwide participated in this campaign, raising critical funds for our programs. Fundraisers donned superhero costumes to embody the spirit of HeartKids, with communities across Australia rallying behind the cause.

- **Two Feet & A Heartbeat Walk:** Two Feet & A Heartbeat is a charity walk for HeartKids families and the broader community to pay tribute to their heart kids and have a moment of reflection for our heart angels. It is held in the form of a 4km walk in multiple locations throughout Australia. In FY24 we had 5,341 registrations, bringing together families, friends, and HeartKids supporters in a unified show of solidarity.



Our Volunteers

Volunteers are the heart of HeartKids, dedicating countless hours to support families and amplify our reach. In FY24, our volunteers contributed to every aspect of our work, from event support to administrative assistance.

Volunteer Contributions:

- **Collection Days:** Volunteers gathered essential items for care packages, family pantry supplies, and activity packs, providing comfort to families during long hospital stays.
- **Event Assistance:** During our Golf Days, Family Days, and other events, volunteers managed logistics, guest registration, and on-site support, enhancing each experience for attendees.
- **Packing Sessions:** Quarterly packing sessions allowed volunteers to assemble care packages for hospital deliveries, providing families with comforting resources during challenging times.
- **Administrative Support:** Volunteers assisted in office tasks and skilled roles such as graphic design, video editing, and content creation, helping HeartKids improve its operations and outreach.

Our volunteers' dedication is invaluable, enabling us to serve families with compassion and efficiency. HeartKids extends our deepest gratitude to everyone who has volunteered their time and skills to support our mission.



Partner Highlights 2024

In 2024, HeartKids welcomed partnership from new business, and retained the relationships with recently established partnerships.

Supercheap Auto's Support for HeartKids

Supercheap Auto, a leading retailer of automotive parts and accessories with over 300 stores across Australia and New Zealand, has been a dedicated major partner of HeartKids for since 2022. Through innovative in-store and online fundraising initiatives and commitment to raising awareness, Supercheap Auto continues to equip and empower HeartKids' mission.

Supercheap Auto has implemented point-of-sale donations in each of their stores, allowing customers to round up their transactions to support HeartKids. The success of this in-store initiative encouraged Supercheap Auto to offer online donations, making it even easier for customers to contribute to a cause close to their hearts. Supercheap Auto's dedication goes well beyond its financial contributions. Their staff enthusiastically participate in the annual Hero for HeartKids mid-year campaign, dressing up as superheroes to engage, inspire and entertain their customers. They have even hosted special visits from Batman and the Batmobile, creating unforgettable experiences for the community.



Creative Partnership: Lilly's Livery Design

One of the most creative and engaging ways Supercheap Auto has showcased its partnership with HeartKids was through the design of their 2024 Darwin Supercar livery. Lilly, a young heart kid, had the opportunity to contribute to the design of their car's livery.

The design was prominently featured on the front page of the NT Times, highlighting both the partnership and Lilly's artistic talent. This creative collaboration not only raised awareness, but brought joy and pride to Lilly and her family.

Supercheap Auto's innovative and heartfelt approaches to supporting HeartKids demonstrate the power of creative partnerships and community involvement. Their efforts have not only provided substantial financial support but also have helped to raise awareness. Together, we will continue to make a meaningful impact in the lives of heart kids and their families in need.

Partner Highlight: Drakes Supermarkets



For over seven years, Drakes Supermarkets has been a valued partner, growing their support from initial participation in HeartKids' Hero for HeartKids campaign to full involvement across all 67 stores in South Australia and Queensland. With point-of-sale 'heart' tokens, Drakes has significantly boosted donations, helping expand HeartKids' reach.

Drakes' team members actively engage with customers during campaign events, fostering a strong community spirit through initiatives like costume days and local fundraisers. In 2022, Drakes launched a scholarship program to support young Australians impacted by CoHD, empowering them in areas like art, sports, and education.



This year, Drakes' efforts contributed to the Hero for HeartKids campaign's success, supporting HeartKids in achieving a \$1,000,000 partnership milestone. Every dollar raised through this partnership provides crucial support to families facing CoHD, and HeartKids is grateful for Drakes' commitment to fostering a compassionate community. We look forward to future opportunities with Drakes to continue supporting these families.



Crown Relocations

Crown Relocations generously extended their partnership with HeartKids into FY2024, continuing to make financial contributions, host workplace participation in Hero for HeartKids, and involvement in Two Feet & A Heartbeat. The valuable partnership continues to evolve, with even greater Crown Relocation staff engagement planned for future HeartKids campaigns.

Mitsubishi Heavy Industries Air-conditioning Australia

Mitsubishi Heavy Industries Air-conditioning Australia (MHIAA) commenced its partnership with HeartKids this year, for the MHIAA Winter Cash Bonus scheme. For each MHIAA air-conditioner that was purchased during the wWinter months, a set percentage was donated to HeartKids. However, MHIAA's relationship extended beyond the scheme agreement, with (insert number) of MHIAA staff participating in Two Feet & A Heartbeat walks nationwide.

Both of the HeartKids partnerships with Crown Relocations Australia and MHIAA highlight the ability for the principal purpose of the partnership to extend into participation for HeartKids campaigns at their workplace. This participation helps to establish awareness and understanding amongst organisational company staff on the mission of HeartKids, therefore bolstering the strength of the relationship.



Workplace Giving

HeartKids is extremely fortunate to be the beneficiary of numerous Workplace Giving programs, via platforms such as Good Company, Good2Give and Benevity.

Workplace Giving is an incentivised means of single donoer engagement with HeartKids, as each donation is made pre-tax. The impact of funds received during Workplace Giving are critical to HeartKids mission.

Matched Giving

HeartKids continued to be the fortuitous beneficiary in 2024 of The Good Guys 'Doing Good' Workplace Giving program, in which donations made by staff to the program are matched by The Good Guys dollar for dollar.

Matched Giving is possible through Workplace Giving platforms (e.g, Good Company, Good2Give), and continues to be an effective means of organisations showing their support of staff donations, effecting both internal organisational relations, whilst also supporting HeartKids with vital funds.



Support for key programs: SA Labor Government, Kiwanis International and the Walker Family:

The development and success of HeartKids’ Early Childhood Intervention Programs—Better Beginnings (0-4 years) and Better Starts (4-6 years)—would not have been possible without the steadfast support of the South Australian Labor Government Department of Health and Wellbeing, Kiwanis International, and the Walker Family. These key partners have provided the critical funding and resources necessary to pilot and refine these programs, which are now being expanded nationally through an innovative hybrid model of online and local delivery.

Better Beginnings focuses on early assessment and intervention, enhancing developmental outcomes for children aged 0-4 by equipping parents with the tools and knowledge to support their child’s growth through everyday activities and play.

Better Starts continues this support for children aged 4-6, preparing them for the crucial transition to primary school. The program builds their social skills, confidence, and readiness to thrive in a school environment, laying the foundation for lifelong success.

Children with congenital heart defects face an increased risk of neurodevelopmental challenges. Thanks to the visionary support of the South Australian Labor Government Department of Health and Wellbeing, Kiwanis International, and the Walker Family, HeartKids has been able to develop programs, referral pathways, and parental capacity-building programs to provide early intervention support. Their contributions have empowered families across Australia, ensuring children impacted by Childhood-onset Heart Disease (CoHD) have the best possible start in life.



Corporate Challenge:

HeartKids celebrates its ongoing relationship with Corporate Challenge.

HeartKids are the beneficiaries of a number of in-kind goods from Corporate Challenge, such as toys and bikes. Often, the recipient heart kids are invited to a Corporate Challenge event, and are presented the goods by the business.

HeartKids could not be more grateful for Corporate Challenges’ generosity, for the ongoing joy that their in-kind gifts provide heart kids.

Roche Diagnostics Australia

We sincerely thank Roche Diagnostics Australia, for over two decades supporting HeartKids through the annual donation of hundreds of CoaguChek INRange meters and a supply of test strips. Donations like these, from the corporate community, help ease the cost-of-living burden and stress for heart kids’ families and allows them to manage their CHD practically, anytime, and anywhere they need.

Thank You

HeartKids is deeply grateful for every individual, organisation, and volunteer who has supported our mission this year. Your contributions enable us to provide life-changing support to families impacted by childhood-onset heart disease. Together, we are creating a future where no person or family faces CoHD alone, and every child has the opportunity to live a healthy, fulfilling life.

As we look ahead to FY25, we are committed to building on our progress, expanding our reach, and ensuring that every CoHD family across Australia feels supported, empowered, and connected. Thank- you for standing with us on this journey of hope, resilience, and compassion.

GOVERNMENT SUPPORT



CORPORATE & PRINCIPAL PARTNERS



MAJOR PARTNERS



Nguyen Household
Pitt Household

Radeski Household
Sharman Household

Wagg Household
Merrell Davis OAM Household

Williams Household
Yager Household

FOUNDATIONS & TRUSTS

Pinnacle
Kingham
Kiwanis
Concert ICT
Younis & Co Foundation
Marian & EH Flack Trust
The James and Jutta Lauf Foundation
UnLtd Foundation
The Lin Huddleston Charitable Foundation
McCusker Charitable Foundation
The Lyone Foundation
Medtronic Foundation
Ian Potter Foundation
CAF America
Keith Irwin Memorial Foundation
Edward C Dunn Foundation
ANDMOR Foundation
GoodCompany Foundation
Chain Reaction Challenge Foundation
Dimmick Charitable Trust

BEQUEST

The estate of the late Elizabeth Mihic

MAJOR SUPPORTERS & GIFTS IN MEMORY (\$5000+)

Magistrates Court of VIC
Variety SA
GIVE Community
Grimbos Building Surveyors
Archibald Household
Berger Household
Bignell Household
Buchanan Household
Iliopoulos Household
Dixon Household
Edwards Household

MEDIA/COMMUNICATION PARTNERS

CocoGun
Initiative Media
VML
Kantar
LightBulb Design
oOh! Media
Seven Network
WriteAway
UnLtd

Thank You

To access the FY2024 HeartKids Limited financial report, please [click here](#) or go to the link on the ACNC website.

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.

We look forward to working with Australian Federal, State and Territory Governments, clinicians, researchers, corporate partners, heart kids, heart teens and adults, heart angel families and the broader CoHD community as we strive to make a real and lasting impact for everyone impacted by childhood-onset heart disease.

Copyright

HeartKids Limited encourages the dissemination and exchange of information provided in this Report. HeartKids owns the copyright to all material produced unless otherwise specified.

All material presented in this report is provided under a Creative Commons Attribution with the exception of HeartKids Logo, content supplied by third parties, and other content as specified.

Material obtained from this Report is to be attributed as: © HeartKids Limited Third Party Copyright.

Wherever a third party holds copyright in material presented in this report, the copyright remains with that party. Their permission may be required to use the material.

HeartKids has made all reasonable effort to:

- Clearly label material where the copyright is owned by a third party,
- Secure permission to use the photograph and or image; and
- Ensure that the copyright owner has consented to this material being presented on this website.

Using the HeartKids Logo or Trademark

The HeartKids Limited or HeartKids Trademark and or Logo can only be used with prior written permission. Enquiries about the use of the HeartKids Trademark or Logo can be sent to office@heartkids.org.au

Disclaimer

HeartKids Limited accepts no responsibility for the accuracy or completeness of any material contained in the Report. Additionally, HeartKids Limited disclaims all liability to any person in respect of anything, and of the consequences of anything, done or omitted to be done by any such person in reliance, whether wholly or partially, upon any information presented in this report.