

Who we are

We are champions of the heart

HeartKids are Australia's champion for people impacted by childhood-onset heart disease (CoHD) which includes both congenital and childhood acquired conditions.

For nearly 50 years we have walked alongside individuals and families facing the challenges of heart conditions from birth and throughout life.

Our mission is clear: support, advocate and care deeply for those impacted by CoHD.

We stand beside families, offering tailored information, resources, and a community that truly understands their journey.

Each year, we deliver support in hospitals and in the community, educational resources, and a referral network to children, teens, and adults affected by CoHD in Australia.







Why we exist

• CoHD is an umbrella term that covers 30+ paediatric heart conditions.

• 8 babies are born everyday with a congenital heart defect - it is Australia's most common birth defect.

 Many more are diagnosed with a heart condition in childhood, including with rheumatic heart disease (RHD).

• CoHD is the leading cause of death of children aged under 12 months in Australia.

• 4 lives are lost to CoHD each week.

• \$2.2B economic cost to the Australian community.

• 250,000 Australians are directly impacted.

• 1 million immediate family members are indirectly impacted by CoHD.

• 6,400 RHD cases, rising by 1,600 by 2030.





How we support

Estimated **250,000** people live with CoHD in Australia.

We directly support 12,500.

You can help us reach more.





1:1 Support from **Support Coordinators:**

- In-Clinic
- In-Hospital
- •In-Community
- In-Region

Peer Support

Early Childhood Intervention **Programs**

1800 Helpline Services

Practical Support

Mental Health Support

Morning Teas

Social Events: adults, parents

Connect Online Community **Support Group**

Camps: Family and Teen

children, youth,

HeartKids

Key Campaign Events:

- Two Feet and a Heartbeat
- Hero for HeartKids

Social

Sweethearts Day

Provisional Resources

Referrals to community groups

Referrals to Partner Organisations

Referrals to suitable support organisations or government departments

Support to access crisis and aid groups Heartbeads

Website **Factsheets**

Parent Information Sessions

From the Heart **Podcast**

CHD Real Talk **Video Sessions**

CHD Directory

RHD Awareness and Information



Resources





How you can help

HeartKids is working everyday to reach more families, but demand continues to grow. With your support, we can expand our reach and be there for every child, teen, adult and family who needs us.

Fund our care

Fund a Support Coordinator. Expand our reach into regional areas and remote communities.

Fund our programs

- Fund a Teen Camp. The camps are a safe and welcoming environment offering support, education, guidance and reassurance at a time of great change.
- Mental health support programs for the entire family.
- Neuro-developmental and early childhood support programs.
- RHD support and prevention in collaboration with communities.

Extend our internal capacity

Fund Digital Transformation. Use your expertise to help us reach and support more people.

RHD support and education

Australia has the highest rate of rheumatic heart disease (RHD) in the world, a condition that is entirely preventable yet continues to disproportionately impact Aboriginal and Torres Strait Islander peoples.

HeartKids work in collaboration with Communities

HeartKids works alongside Aboriginal and Torres Strait Islander communities to support children and families impacted by childhood heart conditions, especially rheumatic heart disease (RHD). We are working with communities to build strong relationships and create meaningful links with healthcare providers and government, while developing collaborative solutions and culturally tailored resources to help prevent RHD. Whether it's navigating hospital stays, understanding treatment, or finding connection, we walk the journey together.





Animation - 'Gemma's Bicillin Day: What to expect when receiving treatment for RHD'

Education and communication piece for children receiving RHD treatment, to inform and help alleviate treatment anxiety.





In-community and regional support

HeartKids is providing community led, culturally safe support for Indigenous communities and those diagnosed with RHD. We provide vital support where healthcare is hardest to access, but demand continues to outstrip our current capacity.

We support around 1,254 families, but many more need help.

In-community and regional support

Reaching families where they live, providing in-community support, including mental health support and neuro development programs.

Helpline and online community

HeartKids Helpline and HeartKids Connect online community for emotional, practical and peer support, at anytime.





HeartKids teen camps

Heart teens describe our Teen camps as life changing. An experience that brings together young people with heart conditions in a safe and fun environment.

Camps are a unique chance to connect with peers who truly understand, build lifelong friendships, and gain skills to manage health and independence.

Teen camps offer education, information and social activities, connecting and empowering teens with shared experiences. The camps aim to strengthen participants physically, mentally and socially.

Teen camps have been placed on hold due to lack of funding.

Sponsor a teen to attend a teen camp for as little as \$1000.











Heart Kid Archie



Diagnosed before birth with complex heart defects, Archie has already undergone two open-heart surgeries and three additional operations due to complications — all before the age of two years.

His family travels from regional NSW to Brisbane for care, often spending weeks away from home, work, and each other.

HeartKids has been there during hospital stays, providing essential items, meals, and emotional support when it's needed most.

"For our most recent visit, I was airlifted up there so I had absolutely nothing with me. HeartKids have meals on the ward for families

and emergency bags with supplies if you've had to rush or just weren't prepared.

This, as well as the emotional support from Simone, is invaluable...

Their reach just isn't far enough, and families like ours depend on what they do."

SHELBY, MUM TO HEART KID ARCHIE



Heart Kid Dominic

HeartKids has been by Dominic's side since birth, providing support for 15 years.

Diagnosed in utero with Hypoplastic Left Heart Syndrome (HLHS), Dominic required open-heart surgery at one week old. He endured multiple hospitalisations and procedures over childhood, including second open-heart surgery at age 12 (2022).

Dominic's family have experienced ongoing emotional, physical and mental impacts, and it is anticipated Dominic will require further surgery in adulthood.

"HeartKids have been like a second family to us. They provided guidance and support from the moment Dominic was born.

Whether it be offering information, an ear to listen when times were tough, providing morning tea to keep us going when we wouldn't leave Dominic's bedside or just providing company.

They introduced us to other families going through the same circumstances, and that has created life-long friendships.

Dominic has been blessed to be a part of HeartKids and has been given some wonderful opportunities to speak publicly about the organisation, which he loves passionately."



Our reach

51KFacebook followers

Aboutes, Advances Tolland

For sharing,

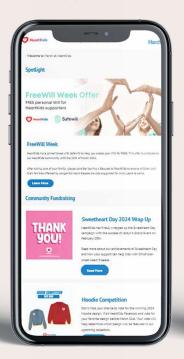
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16K Instagram followers



200K+
Database
supporters

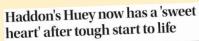


150K eNews subscribers





In the media







Trentham Cliffs' heart warrior

HeartKids calls for fly-in fly-out specialist to be sent to Cairns





harity for children's heart disease is calling for a fly-in fly-out doctor to help Fa



Freddie's 'rough' start shines a light on brave battle of 'heart kids'

WATCH VIDEO





giving thanks for their HeartKids

MS By Michelle Smith June 11 2025 - 2:23pm



An Esperance family is backing a plea to the Government to a plea to the Government to a plea to the Government of the Indian Australian affects one million Australian affects one million Australian Heart disability of the Government and Federal Opposition to ment and Federal Opposition to

ABBEY RUSCOE





Ballarat mums Kimberley Hopper and Stephanie Rogers both know the agony of sitting in a hospital waiting room, wondering if they'll ever take their tiny babies home with them.

Ms Hopper's daughter Delilah, now a healthy nine-year-old, underwent more than 10 hours of open heart surgery at the Royal Children's Hospital when she was just eight days old, after being born with a congenital heart defect known as transposition of the

 $_{
m red\,well}$, but at his six-week check-up, they learned aree separate issues with the valves in his heart. $_{\mbox{\scriptsize now and doing well}}$, but he'll be having more hably next year before he turns two," Ms Rogers said. f all the issues with his heart, his immune system is so every time he gets a bug, he ends up in hospital for a ich is pretty much every month." rs was looking for a childcare centre for Carter and Jenny's Early Learning Centre in Delacombe, where Ms

Have a heart, charity urges all politicians



Family's thanks for support

\$10.5M in-kind media

Total audience reach 39M+



Environmental, social and governance benefits

- Community Impact Program Investment
- Value alignment
- Internal cultural impact
- Co-branding opportunities
- Increased corporate visibility
- Demonstrate social responsibility

Our service delivery partners





for siblings of children and adults with disability/illness















Volunteer. Donate. Participate.



Marcus Sandmann Chief Executive Officer

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HeartKids acknowledges the Traditional Owners of the lands on which we live, work and gather today. We honour their ongoing connection to land, sea, waters and skies, and pay our respects to Elders past and present, as well as any Aboriginal or Torres Strait Islander people joining us today.

