

Supporting heart kids through life



Welcome to the future of HeartKids

HeartKids' strategic goal is clear; we want to give people living with or impacted by congenital/childhood heart disease, regardless of their age or ability, a more effective role in their own treatment.

By doing so HeartKids is supporting them to lead a fulfilling life. HeartKids will give all Australians with congenital/childhood heart disease and their families the best chance of reaching their personal goals, whatever those goals may be.

HeartKids is the voice for those people impacted by congenital/childhood heart disease, the leading cause of infant death in Australia and a complex chronic disease requiring treatment throughout your entire life. For over forty years HeartKids has provided assistance to families, young people and adults living with congenital/childhood heart disease by making available reliable and evidence-based information and timely support, by funding research and making new opportunities possible.

Many people are unaware of congenital/childhood heart disease - and its prevelance in Australia. Some remember the term "Blue Baby" and "Hole In The Heart Baby" - these are terms that describe congenital/childhood heart disease which, in reality, covers a wide range of conditions. At HeartKids, we also include children who may acquire heart conditions such as rheumatic fever and Kawasaki's Disease - therefore we often refer to childhood heart disease which also incorporates heart disease acquired during childhood.

Some startling statistics:

- Eight babies are born with heart disease in Australia every day. That is almost 3000 every year.
- Congenital/childhood heart disease is the single biggest killer of children under the age of one in Australia.
- Approximately half of the children diagnosed with heart disease require surgery to correct it.
- Each week more than four Australians pass away as a result of a congenital heart disease.
- It is estimated that 32,000 children (under 18 years of age) are currently living with congenital/childhood heart disease in Australia.
- Some children acquired heart disease often as a result of rheumatic fever, which is prevalent in many communitites.

HeartKids is striving to increase awareness of congenital/childhood heart disease through various campaign and advocacy programs.

Vision Supporting heart kids through life

Purpose

congenital/childhood heart

Guiding Principles

- Person and family centred Evidence based and informed
- Collective action
- Addressing health inequities
- Accountable governance
 - Wellness focus
 - Sustainable



NAVIGATING YOUR CONGENITAL/CHILDHOOD **HEART DISEASE JOURNEY**

ADVOCACY

HeartKids is the national peak congenital/ childhood heart disease organisation and the voice of people impacted by the disease.

As a leading consumer health advocate we will:

- Advocate for and achieve a National Congenital Heart Disease Action Plan;
- Increase investment in research by Government and others; and
- Gain equitable access to government assistance and support for people impacted by congenital/ childhood heart disease.

INFORMATION

HeartKids is your compass ready to assist you and your family. We will act as your guide to help you navigate your life's congenital/childhood heart disease journey.

As the only charity solely focused on congenital/ childhood heart disease we will:

- Continue to be recognised as the leading source of evidence based and up to date information for people living with or caring for someone with congenital/childhood heart disease;
- Establish an Australia wide congenital/childhood heart disease Referral Program connecting you to partners and stakeholders best suited to assist and support you; and
 - Enhance our reach by tailoring information to meet your needs and circumstances using both technology and face-to-face support.

WHAT OUR GOALS AND PRIORITIES

SUPPORT

HeartKids will enable appropriate, accessible and affordable support to those living with and impacted by congenital/ childhood heart disease regardless of age through an integrated outcomes focused and culturally sensitive suite of services.

By 2020 we will have implemented:

- 2011 Congenital/Childhood Heart Disease White Paper recommendations.
- Project Compass a network of health professionals and peer to peer HeartKids Liaison Workers in each of the ten major cardiac hospitals and key regional centres with an emphasis on support at pivotal points of diagnosis, treatment and transition from adolescence to adulthood.
- Continue to provide and explore new ways of assisting Heart Angel parents, siblings and care givers.

RESEARCH

HeartKids will be a strategic enabler of high quality research into new and improved treatments for, and management of, congenital/ childhood heart disease in children, young people and adults.

By 2020 we will have:

- Implemented a Congenital/Childhood Heart Disease Research Strategy that aligns our priorities with our research agenda;
- In partnership with the Congenital Heart Alliance of Australia and New Zealand (CHAANZ) implemented the bi-national Congenital Heart Disease Registry in turn informing clinical best practice and providing guidance on how to reduce the burden of the disease; and
- Attracted \$10 million in research activities multiplying our research impact.



HEARTKIDS STRATEGIC PRIORITIES FRAMEWORK IN ACTION

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ADVOCACY

Congenital/childhood heart disease is recognised as a priority by government

The physical, social, emotional and economic burden of congenital/childhood heart disease is recognised by the broader community as a critical health issue.

INFORMATION

The community has a good understanding of congenital/childhood heart disease and its impact.

HeartKids services are accessible to all Australians.

SUSTAINABILITY

HeartKids is financially sustainable and positioned to invest in current and new services.

Outcomes

LEADERSHIP & WORKPLACE

Collective accountability for strategy.

Ethical decision-making in governance, program resources, finance and fundraising.

RESEARCH

HeartKids contributes to improving the quality of life and reducing the burden of disease for people impacted by congenital/childhood heart disease through targeted research.

Our research leads to innovations in treating and managing congenital/childhood heart disease.

SUPPORT

Improved health and wellbeing for those impacted by congenital/childhood heart disease including families and care givers.

Reduced burden of disease on individuals, the health system and the broader community.

ADVOCACY

The 2011 White Paper recommendations are actioned and implemented.

Financial support for people npacted by congenital/childhood heart disease in particular NDIS and Carer Benefits (or similar) is achieved.

SUSTAINABILITY

A diverse revenue base is achieved. Remain financially strong and sustainable

\$5 million held in reserve for the congenital/ childhood heart disease Research Trust Fund is achieved.

Measures of success

LEADERSHIP & WORKPLACE

Staff and volunteer retention and engagement remains high. Staff and volunteer motivation remains high.

Innovation and technology is embraced as part of our everyday work.

& WHEN

SUPPORT

HeartKids' programs are accessible particularly for those most in need. ser and partner satisfaction with our

ervices remains high.
Impact measured through ongoing,
validated and independent evaluation
affirms our programs are
making a difference.

ADVOCACY

A National Congenital/Childhood Heart Disease Action Plan is endorsed by government. HeartKids receives funding as necessary to maintain and grow its services footprint.

SUSTAINABILITY

Strong growth in donor engagement particularly regular and planned giving.
Continue to build multi-year corporate partnerships linked to identified priorities.
Increased funding from Trusts and Foundations.

INFORMATION

of our information and support programs has increased.

RESEARCH

Congenital/childhood heart disease research investment measured by

our research partners attracting additional funding Our contribution to the treatment and prevention of congenital/childhood heart disease in high priority areas is acknowledged within the research and broader community.

Increased Government funding for in hospital and community care programs.

INFORMATION

In consultation with special clinicians and services providers, conduct ongoing awareness and information campaigns to create a greater understanding of congenital childhood heart disease.

Outputs

LEADERSHIP & WORKPLACE

Holding ourselves
accountable and having
in place best practice
governance, risk,
human resource, finance
and program policies
and procedures.

RESEARCH

Working collaboratively withCHAANZ to implement the Australia and New Zealand Congenital Heart Disease Registry.

Providing seed funding for investigator led grants, strategic grants, fellowships and scholarships.

Collaborating with strategic partners.

SUPPORT

Delivering Project Compass
by funding in hospital care programs at each major
Australian cardiac care hub including employing
congenital/childhood heart disease Support
Workers and HeartKids Liaison Workers.

Implementing the Peers as Mentors program training volunteers as skilled peer-to-peer educators

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HeartKids is the 'compass' to help you navigate your congenital/childhood heart journey throughout your lifetime.

HeartKids is Australia's leading congenital/childhood heart disease charity and is not government funded.

Donations of \$2 or more are tax deductible.



heartkids.org.au