
Heart Kids

Heart Kids is the only organisation in New Zealand dedicated to providing lifelong care and support for children, young people and families impacted by childhood heart defects (CHD).

We have been here for over 30 years, walking alongside families whose worlds have been turned upside down by the news of their child's heart defect or by learning that their child has acquired childhood heart disease through an illness such as Rheumatic Fever or Kawasaki disease.



Supporting heart kids through life

You are not alone. 12 babies a week are born in NZ with a congenital heart defect - that's one in every 100 births. Heart Kids is here for you and your family right from the start.

Each year, 600 families have a newborn heart child enter their lives. No matter how you say it, the fact is that childhood heart defects is the most common serious birth abnormality in New Zealand.

Every day a child undergoes surgery at Starship Hospital's Paediatric Cardiac Ward, and new parents face the prospect of caring for a chronically ill child.

Families facing this huge challenge need support. They need someone nearby who can listen and offer practical advice and share information, and they need to know they are not alone.

Support where it's needed



Heart Kids is developing a national network of trained support workers who feel passionate about our heart kids, teens, adults and their families.

Caring for a child with CHD means regular trips to Starship Hospital in Auckland for procedures, tests and surgeries. It can mean leaving the rest of the family behind, often not knowing for how long. It can mean a barrage of unfamiliar medical terms. It can mean a lot of waiting and uncertainty whilst a child is in the operating theatre. It can also mean separation, isolation, financial hardship, stress, loneliness, and worrying about what the future might bring.

Returning home from the hospital can also be stressful, as parents and families are left to cope with their very ill child while working to re-establish a new 'normal' for the family. There are so many questions and uncertainties as this is all so new, and families have to come to terms with 'knowing but not knowing'.

Our Regional Family Support teams provide a range of services for heart families in their community, including:

- Access to information and resources, including books and publications written by parents and medical professionals
- Direct practical, emotional and social support from a team of Family Support Workers, through face-to-face home visits and phone calls
- Pre-natal support for expectant parents facing big changes, challenges and decisions
- Help to build support networks and resilience
- Connections with other service providers in local regions
- Connections to other CHD families
- Access to CPR training
- Access to CoaguChek machines and MedicAlert bracelets for children who need them
- Access to camps for heart kids
- Free lifelong membership

*NB: all services provided are subject to the availability of funds

Additional Support Services

- Family Matching:** We know how important it is to be able to talk to someone who understands. We can connect families with others whose children have similar needs, enabling them to share feelings, challenges and experiences.
- Practical Assistance:** We may be able to assist with hospital care packs, food packs, mobile phone vouchers, travel subsidies and other assistance, as resources allow.
- Palliative & Bereavement Support:** As no two heart journeys are the same, please contact us at familysupport@heartnz.org.nz or call us on 0800 543 943 to discuss your situation and how we can support your family.
- Counselling:** Heart Kids can help facilitate counselling support for members where needed.
- Camp Brave Hearts:** A dynamic national camp where heart kids aged between 8 and 12 years can participate in a range of outdoor activities in a fun, safe environment under the supervision of a medical team.
- Camp Teen Beat:** For heart teens aged between 13 and 17 years, this five day outdoor pursuit camp focuses on learning life skills and building friendships, confidence, and self-esteem in teenagers.
- Heart Forum:** Heart Forum gives an opportunity for heart adults aged between 18 and 25 years to attend workshops and training sessions that cover a range of topics. They also have the opportunity to network and build peer support.
- National Conference:** Through lectures, workshops, and open forum discussions, we aim to empower attendees with the necessary knowledge and skills to cope with the day-to-day challenges of living with a childhood heart condition. The national conference is held biennially (funds allowing).

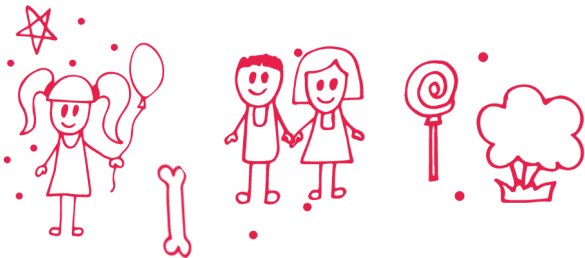
Supporting heart kids through life

Heart Kids is a charitable organisation, and we receive no government funding. We rely on generous support from our wonderful community and donors to ensure we are able to provide the services we do for heart families.

Please make a donation or find out more about how you can help support families and kids today, at www.heartkids.org.nz.

Did you know

- Each year, a number of children will develop a heart condition through rheumatic fever, cardiomyopathy or Kawasaki disease. This is known as an acquired childhood heart condition.
- A congenital heart condition is the most common serious birth abnormality in NZ needing ongoing medical intervention.
- 450 children have open heart surgery each year in New Zealand.
- Annually, 30-40 heart children will lose their battle and become heart angels.
- There is no prevention or cure for a congenital heart condition. Once a heart child, always a heart child.



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For further information:

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HeartKids

Services



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