

2024

Annual Report

Heart Kids NZ

DRAFT





Contents

Pūrākau o te manawa Heart Story: Paige	4
Ngā kōrero a te tiamana Chair Report	6
Ngā kōrero a te Kaihautu CEO Report	10
To Tātau moemoeā me ngā uara Vision, Mission, Purpose & Values	13
Community Family Support Taituarā	14
Hospital Family Support Taituarā	23
Hopuni Camp	24
Pūrākau o te manawa Heart Story: Michael	27
Hiranga Whakatairanga Campaign Highlights	29
Pūrākau o te manawa Heart Story: Lleyton & Lilian	35
Ō mātou kaitautoko Our Supporters	38
Pūrākau o te manawa Heart Story: George	44
Prongo paearu tahua Performance and Financial Information	46



MĀTAU TĀNGATA

OUR PEOPLE

OUR STAFF

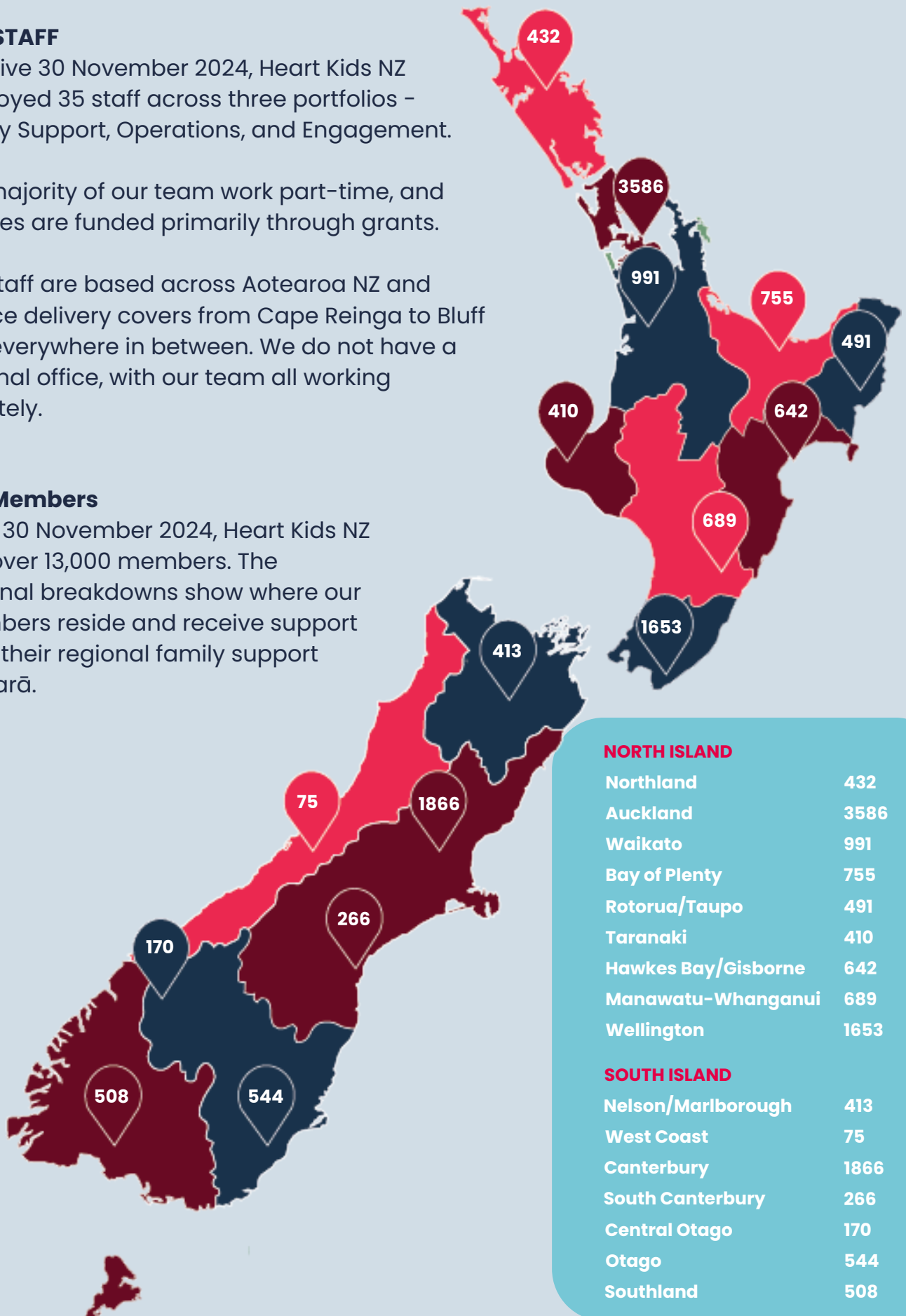
Effective 30 November 2024, Heart Kids NZ employed 35 staff across three portfolios – Family Support, Operations, and Engagement.

The majority of our team work part-time, and salaries are funded primarily through grants.

Our staff are based across Aotearoa NZ and service delivery covers from Cape Reinga to Bluff and everywhere in between. We do not have a national office, with our team all working remotely.

Our Members

As of 30 November 2024, Heart Kids NZ has over 13,000 members. The regional breakdowns show where our members reside and receive support from their regional family support taituarā.



NORTH ISLAND

Northland	432
Auckland	3586
Waikato	991
Bay of Plenty	755
Rotorua/Taupo	491
Taranaki	410
Hawkes Bay/Gisborne	642
Manawatu-Whanganui	689
Wellington	1653

SOUTH ISLAND

Nelson/Marlborough	413
West Coast	75
Canterbury	1866
South Canterbury	266
Central Otago	170
Otago	544
Southland	508



Kōrero pono o te manawa

HEART STORY

PAIGE



Paige has coarctation of the aorta – severe narrowing of the aorta. When she was born the blood supply would be cut off to the rest of her body, there is a duct in the heart that is open when they are in utero – which closes a couple of days after birth as their own heart takes over – her aorta was so narrow that meant she was not going to get any blood supply from neck down.

She had open-heart surgery at 3 days old to fix this. Five days later they had to open her up again because there was a complication and Paige got septicaemia.

“They're there for you emotionally, physically and financially. Families wouldn't be able to do it without them.”

Her vocal cords, which are connected to the aorta, were also damaged by the surgery. It has been an incredibly tough journey for the family, Paige's older sister Blakely died at birth from a heart condition, and mum, Emma, said the family is grateful for the support they received from Heart Kids NZ.



“They were just constantly there making sure if we were okay and there was anything we needed. You just feel so alone. but then you've got all that support. And you just feel so well cared for and acknowledged.”

In hospital and unable to leave Paige, Heart Kids family support



staff would visit and bring coffee. "You couldn't even go and get a meal, so it was amazing when they offered to sit with her so I could go and get some fresh air."

Emma is a paediatric emergency nurse and says she knew a little bit about Heart Kids NZ, but didn't quite understand exactly how supportive they are.

"You know, they're just amazing. They're there for you emotionally, physically and

financially. Families wouldn't be able to do it without them. There's just no way. Even though Paige is doing great, Heart Kids NZ will still be there when she is older, we've always got support from them, which is really nice."





NGĀ KŌRERO A TE TIAMANA

CHAIR REPORT

Tēnā koutou katoa.

It's been another big year for Heart Kids. With twelve children diagnosed with a congenital heart disease or heart disease acquired in childhood each week, the need for our services continues to grow.

Our membership now stands at over 13,600 people, with well over half of our heart kids now heart adults. Once a heart kid, always a heart kid – which is why we provide lifelong support with many of our members continuing to require monitoring, interventions and surgeries throughout their lifetime. Heart Kids is honoured to remain walking alongside our community as they navigate their heart journey.

The vision of our founding members Linda Davies and Michelle Mann as they sat in a windowless hospital room in Greenlane over 40 years ago has never wavered. While Heart Kids may have changed operationally and our services adapted to meet what our community needs today, we're still just as passionate and dedicated to ensuring all heart kids and their whānau fully supported, connected, informed and hopeful for the future.



While we are privileged to have an ever-expanding membership, and in turn rising demand for our work, it does present challenges. We need to simultaneously increase resources and grow our services to provide the support our community needs and deserves. How we navigate this balance has been a focus of the Board and Chief Executive over the last year and as we look forward towards our future, remains a top priority.

What started as a year of change and transition, has ended in a place of stability and focus for Heart Kids. In early 2024 we farewelled Ruth Gorinski who had served as Chief Executive for two and a half years, as well as Senior Leadership Team members Denise Kitto and Sarah Morgan. Later in the year we welcomed David Pimblott as Chief Executive, firstly in an acting capacity and now permanently, as well as Hanna Griffin, Ngaire Lyall and Viv Stark into the Senior Leadership Team.

It was a challenging year for Heart Kids financially. The current high cost of living has seen our events and fundraising activities bring in less income than previous years.

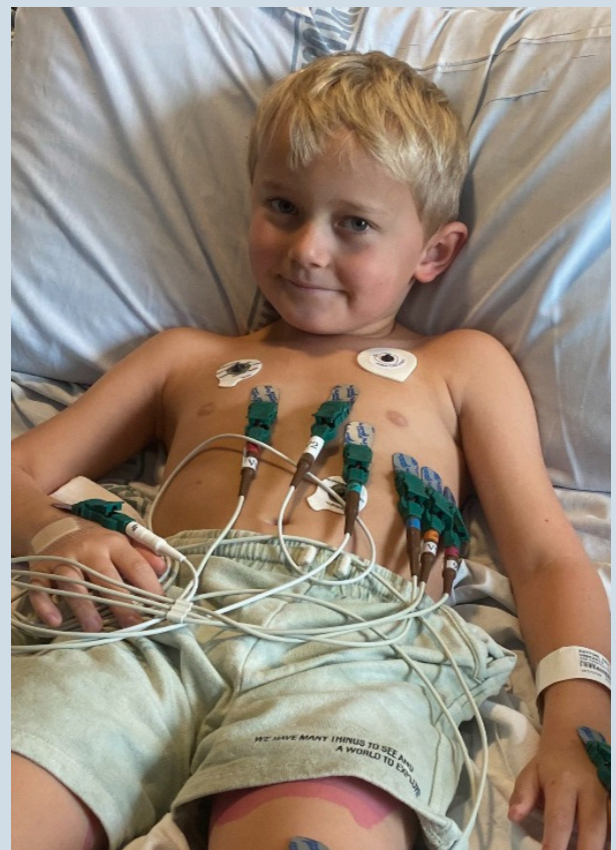
Additionally, the decrease in government funding across the not-for-profit sector has seen more organisations completing for funding and grants in areas traditionally relied upon by Heart Kids. Luckily many of our long-standing supporters were able to continue to provide financial backing and pro-bono support, helping us to buffer funding decreases in other areas – something we are extremely grateful for.

We ended the year with a deficit due to a decrease in income and not wanting to compromise service levels. The shortfall was funded through our reserves which enabled us to continue supporting our members at similar levels to the year before. We remain in a reasonably sound financial position, despite several difficult financial years since the start of the Covid-19 pandemic. The Board remains cognisant of the need to manage our resources judiciously to ensure we remain financially resilient in the face of uncertain economic conditions and growing demand for services. This is also a top priority of the Board moving into 2025.

This year Heart Kids governance Board farewelled Board members Robyn Wickenden, Katie McCrae, Kevin Sharpe and Steve Abley through a combination of individuals term's ending or resignation.

We were also lucky enough to welcome Samir Govind as the Member Elected Representative for the Upper South Island, and Eleanor Koningham and Gina Cheung as appointed members for their Legal and Finance expertise respectively.

I want to thank all Board members who volunteered their skills and knowledge to govern Heart Kids over the last financial year. It's a big workload and responsibility, needing many nights and weekends over the year.



Looking towards the year ahead
With the Board's support of David, and under David's strong leadership, the year ahead is likely to be one of continued stability and focus for Heart Kids. This is also supported by having a strong and dedicated team in place and having invested in improving our organisational culture – both at governance and operational levels – over the second half of the financial year.

Heart Kids must update its constitution and re-register our organisation by April 2026 to remain an active Incorporated Society under the new Incorporated Society Act 2022. This presents the opportunity to reflect on whether Heart Kids' current constitution sets us up well for the future and to deliver the most meaningful and impactful services on the ground where we're needed most.

The Chief Executive and I will host online sessions with our staff, volunteers, branches and interested members in early 2025 to gather input on the changes people think will make Heart Kids better, before summarising this into a draft proposal for feedback.

Once all feedback has been incorporated, the final proposal will be presented to our members to consider and discuss at the AGM in May 2025. While our constitution focuses on governance matters, we've intentionally looked at Heart Kids more broadly, and as a whole, as there are no doubt other, non-governance related ways, to improve Heart Kids, its operations and support to members.



The Board will continue to monitor Heart Kids finances carefully this year knowing it's likely to continue to be a year of increased competition for philanthropic funds coupled with continuing high cost of living. We recognise in these economic conditions make it a big decision for individuals, businesses and corporates to make donations or to the level of generosity that's been easier in previous years or stronger financial times.

Everything we do is made possible because of the generosity of others. Heart Kids is a club you don't know exists until you find yourself a member. But alongside what is often a complete shock and incredibly difficult journey, many of those who find themselves as heart kids and heart whānau find a silver lining in being part of community of resilient, empathetic and supportive people who've walked the same path before them.



We're lucky that many people feel so much gratitude for the support they received in their most difficult moments that they chose to give back. We couldn't be luckier to boast the number of volunteers we do.

With every person who gives back – be it donating, fundraising on our behalf, or becoming a volunteer to support a local regional branch, run a branch or govern our organisation – Heart Kids is better enabled to serve our community. It allows us to provide value to our members far in excess of what our financial resources alone would allow.

Our organisation's staff are exceptional, always going the extra mile for our families, and with the utmost dedication, passion and skill.

As a Board, we cannot thank our staff enough for what they do. They work tirelessly to bring the Heart Kids vision and mission to life and are both the heart and backbone that holds our community together. A special acknowledgement goes to David Pimblott, our Chief Executive, who has provided strong leadership and stability for our organisation in 2024.

Our heart kids and whānau need support and services despite tough economic conditions, so we couldn't be more indebted to those who have financially supported us in 2024 when every dollar has really counted. Thank you to all of the organisations who provided grants, business and corporates who provided sponsorship and individuals who provided donations.

Ngā mihi nui ki a koutou katoa – our sincerest gratitude to you all.

Ashlee McCormick, Board Chair



Ngā kōrero a te Kaihautu

CEO REPORT

It is my absolute pleasure to present my first CEO report for the Heart Kids NZ (HKNZ) Annual Report 2024.

Since commencing my role with HKNZ, a special acknowledgement should be made with regard to the commitment of the whole team at HKNZ, during a time of significant organisational change. I would especially like to acknowledge the personal support of so many of the dedicated HKNZ staff, there are too many to list and to thank individually but it is their belief and trust in me that has made my job possible. I cannot thank them all enough for their unreserved confidence in me, to support them, and the incredibly important work of HKNZ in the community.

I would also wish to formally acknowledge the support of the Board, and in particular the input and encouragement from Ashlee McCormick, the HKNZ Board chair. In my opinion I would not have been able to progress my role at HKNZ without the Board's endorsement, but most especially Ashlee's personal support.

In my brief time with Heart Kids, I have become incredibly invested in Heart Kids and I don't think anything resonates more with me as to the very essence of what Heart Kids is all about, than the brief summary, in part extracted from the HKNZ Statement of Service Performance (SSP).



Heart Kids provides vital practical and emotional support for children, young people, and adults living with congenital and acquired childhood heart conditions, and their families. Our services include tailored family support in the community and hospital, resources to navigate life with a heart condition, and events that foster connection and resilience. By partnering with health professionals, businesses, education and community groups, we ensure that every heart family can access the support and information they need on their heart journey.

HKNZ is proud to support a community of over 13,000 members across Aotearoa. Our reach is nationwide, with a dedicated team of 7 full-time and 21 part-time staff working across our family support and engagement and operational national support teams. This ensures that we can provide tailored, timely support to our members wherever and whenever it is needed. But most especially together, we are united in our mission to support all those impacted by congenital and acquired heart conditions.



HKNZ is a provider of nationwide community family support services via an absolutely dedicated and again inspirational family support team led by Ngaire Allen. Our network of Taituarā throughout the country, from Auckland, Starship hospital, and regions nationwide, delivering wherever possible personal or at the very least remote support, are the backbone of the services we provide to support our families. By maintaining contact with our families via murmurs coffee groups, networking events, facilitating clinics and just being there wherever and whenever our families need you.

Personally, it has been incredibly special for me to meet heart families and heart adults at family support events, be that with heart adults or parents and heart kids. I am just so thankful for the opportunity to work, but most especially to support you.

Heart Kids NZ receives no government funding, we have a small, dedicated engagement team, led by Hanna Griffin, who do an incredible job. I am genuinely in awe of the work these folks do, the level of commitment, and as I say, the dedication of this team is in my opinion unparalleled. Everything from managing our grant funding programme, sourcing and maintaining relationships with donors and other supporters, to managing and coordinating the amazingly successful national fundraising campaigns such as Heroes for Heart Kids, and Little Heart Day. To managing our brand, coordinating not only the consistency of our messaging for both internal but most especially our external communications, by social media, newsletters with our supporters, volunteers and our members.

All of this fundamentally underpins the ability for us to be able to deliver via our family support team the services and support for our heart kids' community. You are incredible and I cannot thank you enough as a team for your efforts and support not only for Heart Kids but for me personally.



I should also make special mention of the numerous regional fundraising events often facilitated by our Taituarā, but also a network of local volunteers – often this is coordinated by local branches and again our local volunteers. These events continue to lift the awareness of Heart Kids but most of all provide the opportunity for our families and volunteer community to not only raise funds, and engage with local businesses, but also network with themselves to support other local families.

From an administrative perspective our operations team led by Viv Stark, ensures that there is consistent management and coordination of a myriad of tasks such as our systems, payroll, staff expenses, travel, insurances etc including liaison with our external accounting services providers. All these services are absolutely essential for Heart Kids to operate and function as an organisation. I am so grateful to this team who act as the “glue” that blends the organisation together.

Heart Kids has an incredible network of supporters be they again the incredible volunteers, or our amazing financial supporters, the donors, the trusts and foundations everything you do, every dollar you give to Heart Kids really does make a difference. I can't thank you enough.

It is my absolute privilege to do all I can to support Heart Kids and the families in the community. In particular that our families are not alone on this journey from hospital and birth to adulthood. As the expectations and level of support inevitably changes but most of all there is continuity in our vision that at all times our community should indeed feel supported, connected, informed and hopeful for the future.

Working with an incredible and amazing team all of whom, along with our Maia bear mascot, are truly my inspiration and enable me to say with sincerity that after over 30 years of working in the business and corporate world “I have found my place”.





To Tātau moemoeā me ngā uara

VISION, MISSION, PURPOSE, VALUES



Vision

All people affected by congenital heart disease and heart disease acquired during childhood (CHD) will feel fully supported, connected, informed and hopeful for the future.



Mission

Our mission is to provide lifelong support for all affected by the world's most common birth difference or heart disease acquired during childhood



Purpose

Heart Kids NZ is the compass to help our members and their families and whanau navigate their heart journey throughout life



Values

Heart children and their families first
Respect with compassion
Education and empowerment
Integrity at all times
Passionate and professional
Commitment to success



Taituarā

Community Family Support Taituarā

At the heart of Heart Kids NZ is our family support team – a group of dedicated, down-to-earth Taituarā who walk alongside heart whānau through every stage of life. From the early days of diagnosis to navigating school, work, relationships, and the big milestones in between, they're there to offer support, guidance, and connection.

Living with a childhood heart condition can be tough – not just for the child, but for the whole whānau. That's why our support is practical, personalised, and grounded in real relationships. Whether it's checking in with a family who's just come home from hospital, helping a teen prepare for transition to adult care, or simply being someone to talk to – our Taituarā are there.

They also help bring people together. Through Murmurs coffee groups, local family events, and one-on-one support in the community, they create spaces where heart families can connect, share their experiences, and feel a little less alone.

It's not a one-size-fits-all approach – just the right kind of support, at the right time, from someone who truly understands.



Reaching Across Aotearoa

Heart Kids NZ supports a nationwide community of **13,683** members, including:



5,392

DIRECT CLIENTS

Children, teens, adults, prenatal cases, and 283 heart angels who are lovingly remembered.



8,291

FAMILY MEMBERS

Parents, siblings, and caregivers who play a vital role in every journey.

Heart clients supported (both community and hospital)



Our team of 19 family support taituara, both in the community and hospital, provided direct support to 3,275 heart kids whanau this year. This support is tailored to suit the need of the families as they are on their individual journey. This ranges from texts and emails to home visits as well as both local and online events for all ages. Our team are incredibly proud to walk alongside heart kids and their whanau.

3,275

In person contacts (both community and hospital)



Our team, both in the community and hospital, support whānau with home and hospital visits. The majority of this number is when our hospital team pop in to see whānau on the wards in both Starship and Auckland City hospital – their friendly faces are often the consistency our families need as they navigate their hospital stay.

2,130

Maia Bears given out



Our mascot bear 'Maia' is the special friend a heart kid or adult is given when they are in Starship or Auckland City Hospital. Maia encourages heart kids and adults to be brave through their journey, and often comes back on consecutive visits and stays.

160

Cardiac Clinics attended

Our community Family Support Taituara attended 90 cardiac clinics this year around the motu, providing support and often an extra set of ears (or hands!) for whānau on the long days at local visiting cardiology clinics in their regions. This is also a time for the CFST to create relationships and connections within the hospital system to better support our whanau.

90

Murmurs + family events



We held 221 in person events around the motu. This provides a time for families to come together and a chance to meet others in similar journeys who they can relate with. A time for heart kids to meet other heart kids who also have scars and stories to tell. Feedback from our families is that they enjoy these events and often have a "me too" connection with somebody else; to know they are not so alone in this journey.

221

22

Bereavement

We have a saying in Heart Kids NZ – once a heart kid, always a heart kid. This is the number of heart kids we sadly lost this year. Our support continues beyond this journey and we are incredibly grateful that this year we have had Bunnings come on as a partnership to provide Bereavement gifts for our taituara to provide support for whanau.



1,051

Care packs (community and hospital) and vouchers given

This is the number of whānau who were provided with a care or gift pack and vouchers this year. These often contain little treats and toys to put smiles on faces in such a worrying time. On the wards our taituarā give out Subway, Sushi, Supermarket and petrol vouchers to make the time a little easier for families – being given something as small as a \$20 subway voucher can mean so much to a family who are financially bearing the time away from home and work in hospital.



183

Referrals to other agencies

Our family support team refer to other agencies when opportunities arise for our heart kids' whanau to partake in incredible activities – these include Korucare, Uplift in Kind, Embracing Hearts, Corporate Challenge and Make a Wish. This provides our families with a special time, away from hospital, to create memories and we are incredibly proud of the connections we have to be able to do this.



78

Camp

Our annual summer camp is always a fun start to the year. Lots of fun to be had for heart kids, but also incredible for parents to know that their heart kid with medical needs is in a safe environment with medically trained staff to help if needed. The experiences and opportunities camp provides is huge – and the smiles are just as huge at the end of each camp.



Our People, Our Purpose

"It's a privilege to be able to use my health knowledge and lived experience to help support fellow heart adults across New Zealand.

I enjoy helping to create opportunities for heart adults to connect, have fun and help support each other".

- Michael



"What being a Taituara means to me is supporting families in various ways, whether its running family events for connection , organising meals to take one more thing of a family's mind or meeting them for a coffee and a chat. It's amazing what a listening supportive ear can do for families."

Tash

"The thing that I enjoy most about my role is being able to support families through a really tough time in their lives, and to help allay their fears in some way about the heart journey they are on. Sometimes I can contribute to that, and sometimes it is other families who have been through the same thing that can do that. I had one mum come to me after our Christmas Party last year who was awaiting a possible trip to Starship with her wee boy. She said "Leeann, thanks so much for organising this, I have spoken to three families who have been to Starship and they all said it is all okay, there is so much support available, you are helped every step of the way, and it isn't something to be anxious about. I feel so much better." That to me highlights what Heart Kids is all about."

- Leanne



"Not all of us can do great things. But we can all do small things with great love". (Mother Teresa). This quote undergirds and informs my work with our Heart Kid families. I cannot solve the problems our families face. What I can do are small things – small gifts, home baking, a visit, a coffee, a "I'm thinking of you" text – to let someone know they do not walk alone. I do these things with the love I believe all human beings are worthy of. Whilst not 'big', I believe these small things are transformational in our families' lives."

- Julie

"The best way to describe my role as Family Support Taituara is that it is a privilege. To be welcomed and trusted by whanau when they are at their most vulnerable, to genuinely empathise with them when they are scared and feel like nobody truly understands the emotional rollercoaster that is being the parent of a heart warrior, is an honour. In my role, I am not just a support person, but a companion on a journey that is often filled with uncertainty, fear, and moments of incredible strength. I am here to listen, guide, and ensure that they know they are not alone. Through every challenge, every setback, and every victory, I am privileged to be part of their journey, providing not only emotional support but practical assistance to help them navigate a world that often feels overwhelming.

As a Family Support Taituara, my role goes beyond just offering advice. It is about building relationships, creating a safe space where whanau can express their worries and hopes, and walking alongside them as they navigate the complexities of caring for a heart warrior. The trust placed in me is something I do not take lightly, and it inspires me every day to give my best to the whanau I serve."

- Jo



"The journey of being a Heart Kid is a rollercoaster of a ride, and it feels like such a privilege to be in a role that provides support throughout this journey. A care package delivered when they arrive home from hospital, a coffee and some cake and chance to catch up or tickets to some amazing events. If I can bring a smile to someone's face or temporarily lighten the load, my role as Family Support Taituarā has been achieved."

- Vicky

"Working with a such an amazing team, who along with our Maia bear mascot, are truly my inspiration to support, our incredible heart families in the community and enable me to say: "I have found my place".

- David



"I love doing my job as a Taituara, love being able to give back to the heart kids community and share some of the support I received as a Heart Mum. Favourite moments have been hearing that having worked with a family in the lead up to surgery it made it that much easier on the family as they were more prepared, and recently at an event I was able to introduce a family of a 5yr old with TOF to a heart adult who has the same condition, the family were so grateful as they said it gave them hope."

- Mel



"Being a heart mum myself I know first-hand how much it means to our families to receive support during some of the darkest moments of their lives. It is a privilege to connect with organisations and individuals in our community who share our vision of walking alongside heart kids and, through their incredible generosity, enable us to continue our important mahi."

- Barb

"Being able to make even the smallest impact in someone's life is incredibly special and rewarding. I'm in awe of the strength, resilience, and courage our heart warriors and their families have and it's a privilege to walk alongside them in their journeys."

- Narelle



"It's always a privilege to walk alongside someone's journey, it allows me to offer support, and witness the families resilience first hand."

- Kat



"Every dollar we raise, every campaign we bring to life, is about honouring the strength of heart kids and their whānau. We fight for visibility and funding so we can give more - more support and more connection. Heart Kids NZ is built on the courage of every child, teen, and adult with a childhood heart condition. We do this work to give back - so that no whānau ever feels alone on their journey, no matter where they are in Aotearoa. It's an honour to be part of this incredible community."

- Hanna



"I'm always in awe of the strength and kindness of our heart whānau. The way our community shows up for each other is something really special. And when heart angel families choose to be part of that - giving back in honour of their precious tamariki - it's deeply humbling.

Those moments stay with me. Our work matters so much because our heart kids and their families are incredibly special people, facing challenges most can't see, with courage and love that deserves to be seen and supported."

- Laurel

"It is a true honour to be trusted to walk alongside our families as they navigate the unknown, to be a small ray of hope, to let them know that they are not alone in this journey. For me it seeing them take a deep breath once they know that what they are feeling is valid, it's when they smile through tears and say how amazing it was to meet someone further along in the journey. It's welcoming them into a community who will support them going forward and knowing they have ongoing support. It's those simple moments that make the world of difference. "

- Montee



"For me, working for Heart Kids NZ means supporting a special cause- standing beside the heart families who have shown so much courage in their journeys and offering connections and events within the community for them to enjoy." - Amanda

"As the National Administrator and essentially working 'back office', it is always so rewarding when I get the chance to see our heart families first-hand. Whether it is at an event or at camp, seeing the smiles on children's faces when they get to mix with other children who have been through the same issues as them makes for beautiful friendships for both the children and parents. It brings the realisation that everything we do makes such a positive difference to our heart families." - Veebha

"Helping and supporting families is the best but being able to show them that there is hope is even better" - Ismay



"It is an honour and a privilege to work alongside the Heart Kids NZ community – witnessing the courage, growth and incredible friendships made at camp is nothing short of inspiring. Our brave heart kids remind me every day what true strength looks like.." - Bec

"He aha te mea nui o te ao? He tangata! He tangata! He tangata! Hei. What is the most important thing in the world? It is people! It is people! It is people! This is a well-known and often quoted whakataauaki in Aotearoa. The saying highlights the importance of people and their wellbeing. Many of us at Heart Kids NZ are here because we have a genuine aspiration for healthy people and communities. I am very proud to work with a team who on a daily basis put the support and wellbeing of heart families at the centre of their efforts, providing a listening ear, a meal, some time out, sharing a laugh or making great memories. This support is often during times that families are at their most vulnerable and I have met with a variety of heart families, teens and adult who all speak fondly of their Family Support Taituarā and who feel the connections they make and continue to make give them hope and confidence on their journey." - Ngaire

"I feel privileged to play a small role in someone's heart journey. I know firsthand how tough a road this is and I find it an honour to help others walk it." -

Elaine



"I feel privileged to get to walk alongside our families, often during the hardest times, to be able to support them as they navigate life with a heart kid. It brings so much joy to see these fragile babies grow into bigger kids who are so brave and resilient, and know that I helped their parents journey be a little easier by being there for them. It isn't always smiles and rainbows and too often a home visit or phone call can bring tears and conversation about worries, but I walk into those visits hoping that by them being able to share their worries and tears that it has made their journey maybe just a tiny bit easier. Seeing our families in hard times, and sadly that is sometimes that is the death of their heart kid, is hard – but being able to say that we are here for them now, and in the future too, I know is comforting for our families. "

- Claire

"I like to feel useful and that I've been able to do something to make a positive difference to that person today. The hardest part we part for Amy and I is seeing families in distress and the trauma that they go through. There can be many layers of trauma and we have so much respect and admiration for how families cope, often showing great resilience, patience and strength." -

Ashley



"It may be just something small like getting a coffee and slice someone who's having a bad day to cheer them up and to let them know we care. We know that once we connect new people with HKNZ that the lifelong support will be there for them and they become part of a family. "

- Amy



Support When It's Needed Most

For families in hospital with a child facing heart surgery or treatment, the days can feel long, uncertain, and overwhelming. Many are far from home, separated from partners and other children, juggling the emotional toll of their child's condition with the practical realities of life: parking costs, travel, bills, disrupted routines, sleepless nights, and the constant fear of what might lie ahead.

While there's no cure for a childhood heart condition, there is support – and inside Starship Hospital in Auckland, that support comes in the form of Amy and Ashley, Heart Kids NZ's two hospital-based Family Support Taituarā.

Amy and Ashley are a steady and compassionate presence for families navigating some of the most difficult days of their lives. Each morning, they visit the wards, checking in with families they've come to know and introducing themselves to new ones. They offer a listening ear, help people find their way around, organise parking vouchers, restock the freezer with meals, and sometimes just sit with a parent during a hard moment. It's in these small but meaningful acts that the real impact of their work is felt.

Their support goes beyond the bedside, too. From hosting weekly morning teas for parents to checking in with babies in NICU and heart adults receiving care, they walk alongside families across many parts of the hospital. They work closely with social workers, psychologists, and hospital staff to make sure families have the emotional and practical support they need, when they need it most.

There's no one-size-fits-all approach. Every family is different, and Amy and Ashley adapt to what each whānau needs – whether it's a coffee and a chat, a moment of quiet presence, or a shoulder to lean on. What they do may not change a diagnosis, but it helps lighten the load.

The connection doesn't end at discharge either. Through close coordination with our regional teams, families continue to receive wraparound support back home, ensuring no one faces the journey alone.

Amy and Ashley's work is a reflection of Heart Kids NZ's values in action – compassion, community, and care. And in the midst of hospital corridors and clinical routines, they offer something simple but powerful: humanity, heart, and hope.





HOPUNI

CAMP

In January, more than 80 heart kids and teens from across Aotearoa came together at Woodend Christian Camp for a week packed with fun, friendship, and firsts. From the moment campers stepped off the bus, it was clear this was going to be something special. For some, it was their very first time away from home. For others, it was a chance to reunite with old friends and try new things. And for everyone, it was a place where they could truly be themselves – surrounded by people who understood what it means to grow up with a heart condition.



The days were full of action: ziplining through the trees, racing go-karts, bouncing on the aero jump, conquering the climbing wall, and diving into the waterslide. Evenings brought dress-up nights, dancing under the stars, and stories around the campfire.

Favourite moments? There were too many to count.

"The go-karts, because of the adrenaline."

"The zipline – I loved pretending I was flying."

"Aero jump – it felt like zero gravity, and I did 11 backflips!"

"The soft toy we got on the first night was so cool – it was nice to cuddle when I missed home."



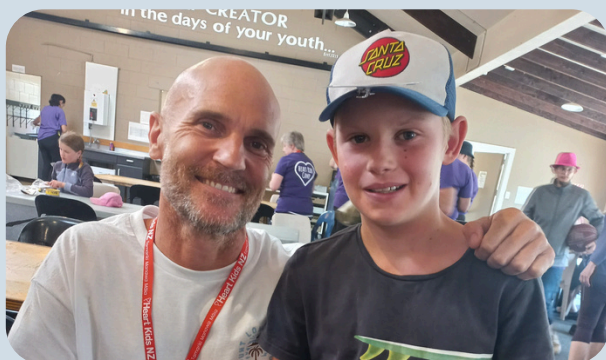


HOPUNI

CAMP

Mealtimes brought their own kind of magic. *"At breakfast, lunch and dinner, me and my friends made a beat and started singing We Will Rock You by Queen."*

Behind every laugh, leap, and late-night chat was a team of caring volunteers – the "purple shirt people" – who helped make camp safe, supported, and unforgettable. One camper said, *"They were really nice and helpful. I felt well cared for."*



We were also thrilled to welcome our Heart Kids Ambassador, Ben Barrington, to camp – a visit that created plenty of buzz and selfies!



This incredible week wouldn't be possible without the generous support of our funders and sponsors. A huge thank you to the Lindsay Foundation, Rātā Foundation, Newman's Own Foundation, Lion Foundation, and Supercheap Auto – your kindness gives heart kids this special chance to grow in confidence, courage, and connection.

As one camper simply put it: *"Everything. I loved everything."*



"It was amazing. I loved meeting new people and hanging out with everybody because I'm an extrovert."



"Seeing all the other heart kids made me feel like there wasn't just three or four of us in the world – there's way more than I knew."

"Trying things I've never done before made me feel scared – but good, too."



"It was a great experience. I loved meeting people with similar stories."





Kōrero pono o te manawa

HEART STORY

Michael



For Michael Bowey, living with a congenital heart condition has meant facing multiple open-heart surgeries, long recoveries, and the emotional weight that comes with managing a lifelong health journey. But it has also meant discovering deep purpose in helping others do the same.

Born with a serious congenital heart condition called pulmonary atresia, Michael underwent his first open-heart surgery at just three weeks old. Since then, he has had multiple complex surgeries, including a pioneering valve-sparing procedure for an aortic aneurysm, and has spent a lifetime managing his health with strength, optimism, and determination.

“

It's a privilege to be able to use my health knowledge and lived experience to help support fellow heart adults across New Zealand.

”

Despite these challenges, Michael's life has been full — from playing sport in his teens to a 20-year nursing career and even running two half marathons in his 30s. Today, he draws on those experiences in his work with Heart Kids NZ.

Now, as Heart Kids NZ's National Heart Adult Taituarā, Michael uses his personal experience and professional background in nursing to support heart adults all over the motu. From one-on-one guidance and hospital check-ins to building community through online spaces and virtual meetups, Michael's work is helping ensure that heart adults don't walk their journey alone.

In 2024, Michael travelled to Dunedin to connect with cardiac specialists, helped celebrate Pride Month with an online quiz, and shared his story through the Harps for Hearts charity event. He worked closely with our hospital support team to connect with heart adults post-surgery and distributed our new Heart Adult support brochure to health professionals across the country.



"I enjoy helping to create opportunities for heart adults to connect, have fun and help support each other."

Why It Matters

Support doesn't end in childhood. Heart Kids NZ is proud to offer lifelong care through Michael's work - helping heart adults stay connected, informed, and empowered, no matter where they are in their journey.

Whether someone is newly transitioning into adulthood or has been living with a heart condition for decades, Michael is there with trusted information, a listening ear, and a strong sense of community. His lived experience is a powerful reminder: while a childhood heart condition never goes away, no one has to face it alone.





Little Heart Day



Little Heart Day (LHD) has become one of Heart Kids NZ's most treasured campaigns – uniting early childhood centres, schools, workplaces, community groups, and our heart whānau across Aotearoa in a powerful show of aroha.

In 2024, the nation once again rallied behind our cause, with our community of passionate supporters stepping up to raise vital funds and awareness for childhood heart conditions. Iconic landmarks across the motu lit up in red, standing tall in honour of the 12 babies born every week with a childhood heart condition.

“

*A little heart can
make a big impact*

”

A highlight of this year's campaign was our personalised text-to-donate initiative, allowing families and supporters to share their unique heart journeys and fundraise in honour of heart kids close to their heart. This deeply personal connection gave many in our community a powerful way to raise awareness, celebrate resilience, and honour those impacted by CHD.



We are incredibly grateful to every person, whānau, and organisation who took part. Your commitment helped lift the voices of our heart community and reminded us all what it truly means to stand together.

Thanks to your support, Little Heart Day raised over \$80,000.





Heroes for Heart Kids

Our annual street appeal, Heroes for Heart Kids (Heroes), returned with powerful momentum in 2024 - bringing together everyday heroes from across Aotearoa to raise awareness and vital funds for our heart heroes.

We kicked off with a digital "shake-a-bucket" centred around a bright, fun, hero-themed text-to-donate campaign. Designed to be kid-friendly and engaging, Heroes became a vibrant nationwide movement throughout September - culminating in our much-loved street appeal.

On the 27th and 28th of September, staff and volunteers took to the streets (many dressed as superheroes) collecting donations and sparking important conversations about the realities of childhood heart conditions.

Key highlight this year was our partnership with USL and Philips, who helped amplify the campaign through the nationwide launch of Philips AEDs. We were incredibly grateful for their support - raising awareness through their networks.

Thanks to the combined efforts of our amazing volunteers, supporters, and workplaces like Bunnings, the campaign raised over \$85,000. This total, achieved through street collections, online donations, and corporate support, reflects the deep generosity of New Zealanders and their commitment to uplifting our heart community.

We're especially grateful to our staff and volunteers, who gave their time, energy, and heart to this cause. Your compassion and enthusiasm created real impact - not just in the funds raised, but in helping more people understand the lifelong journey of living with a childhood heart condition.

To every supporter, partner, and hero who stood beside us, thank you. This campaign continues to prove the incredible things we can achieve when we come together for something that truly matters.







Heart Stopper Challenge

The Heart Stopper Challenge continued to bring the chill and the thrill in 2024, with brave participants across Aotearoa plunging into icy water to raise awareness and funds for children and whānau living with childhood heart conditions.

Events were held in Auckland, Hamilton, Manawatū, Wellington, Christchurch, and Dunedin, with a mix of incredible community venues and supportive hosts – including Bunnings, who kindly facilitated events in several locations.

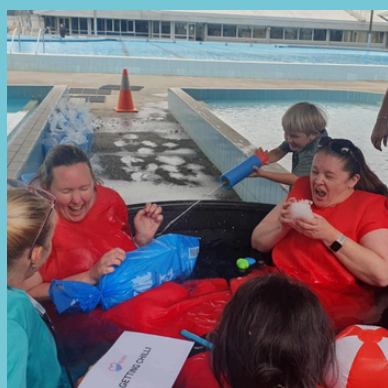
Participants took on the challenge of sitting in icy water for six minutes, symbolising the slush surgeons use to cool and protect young hearts during open-heart surgery. Many got into the spirit by dressing up in creative costumes, creating a fun and memorable experience that also sparked meaningful awareness around the lifelong impact of childhood heart conditions.

This year's campaign raised almost \$55,000 – a drop from previous years, due in part to our small organising teams and a busy 2024 calendar, with the event taking place closer than usual to our Heroes for Heart Kids street appeal and other key fundraising and family events. While the total was lower, the passion and commitment from participants and local organisers was as strong as ever.

We're incredibly grateful to everyone who got involved—from the brave souls who jumped in the ice, to the volunteers, donors, and communities who rallied behind them. Your support means everything to our heart whānau.

Together, we turned cold water into warm hearts!







Lleyton & Lilian



Lleyton was born in October 2010 with Tetralogy of Fallot and at 6 weeks old he had his first open heart surgery. He spent his first year of life in and out of hospital with multiple health conditions and had a cardiac catheter procedure to balloon his narrow pulmonary arteries when he was 8 months old.

After this, he had another 5 or so cardiac catheter procedures in Starship over the next few years to balloon or place stents, and after he collapsed at school as a 6-year-old he had a reveal device placed under his skin to monitor his heart at all times.

“They're there for you emotionally, physically and financially. Families wouldn't be able to do it without them.”

Claire Sword, Lleyton's mum, said when he was only 2.5 years old, they handed their little boy to the surgeons to fix his broken wee heart. “It was soon after this, that Lleyton was then diagnosed with Long QT Syndrome, a hereditary heart condition affecting the electrical side of the heart that many of our family have.” Claire also has Long QT Syndrome.



This meant Lleyton would be on lifetime medication and have an automatic external defibrillator (AED) in a bag that goes everywhere with him.



Lleyton became a big brother in 2012 and 2015 to his sisters Stella and Lilian. They were both tested for Long QT Syndrome and at 1 year old it was discovered that Lilian too, had the gene. Lilian also went onto medication and was given an AED to have at home with her, because Long QT Syndrome can cause cardiac arrest.

Lleyton is now 13 years old and currently waiting for the phone call with a date for his next open-heart surgery, but he doesn't let this stop him from living his life. He is cricket and basketball mad and loves nothing more than hanging out with his mates and has talked about working in the medical field when he's older.





Lilian is now 8 years old and thankfully having Long QT Syndrome hasn't had too much of an impact on her life thanks to her medication. She was lucky enough to attend the Heart Kids NZ camp this year and loved meeting other heart kids like her. She loves hockey and dancing and creating anything she can craft with she will!

She is empathetic and so caring, which I put down to being born into a family where her big brother faces so much.

Claire said their family life to many might seem chaotic, filled with hospital appointments and worry about the future but they are so thankful for the opportunities they have been given and the people they have met throughout this journey too.

"Heart Kids NZ has provided us with support, resources, advice, knowledge and connection with other families, but most importantly hope. I remember the first Heart Kids NZ event I attended when Lleyton was this tiny little baby, blue with low oxygen saturation and an NG tube in his nose to feed him."

Claire said seeing the older heart kids running around and having fun, smiling, laughing and living life gave them so much hope. "And now I look at Lleyton and Lilian, and all they have been through, and hope that their journey now inspires others embarking on theirs, just like it did us."





Ō MĀTOU KAITAUTOKO

OUR SUPPORTERS

Supercheap Auto



If you've ever walked into a Supercheap Auto store during one of their fundraising campaigns, you'll know just how committed their team is to helping heart kids and their families. Over the past 14 years, Supercheap Auto has raised more than \$2 million for Heart Kids NZ – an extraordinary achievement that reflects their deep and ongoing commitment to our cause.

What began as a short-term initiative quickly grew into a powerful, long-standing partnership. Supercheap Auto originally planned to support a different charity every six months, but after seeing the impact of their efforts

– and meeting some of our heart kids and whānau – they decided to focus their energy on helping Heart Kids NZ for the long haul. And we're so thankful they did.

Supercheap Auto's nationwide campaigns bring together passionate staff and generous customers, all working towards a common goal: to make life a little easier for children living with childhood heart conditions. From donation drives at the till to community events and visits to camp, their team brings heart, energy, and a whole lot of joy to everything they do.



Ō MĀTOU KAITAUTOKO

OUR SUPPORTERS

Supercheap Auto



To the team at Supercheap Auto and every customer who's made a donation at the checkout: thank you. Your support has helped fund vital services for heart families all around Aotearoa. We simply couldn't do it without you.



Business Manager Mat Northway describes his first visit to a Heart Kids camp as a "heart opener" – a moment that made the cause truly personal. "What these kids go through, and their extended whānau, too... it's a privilege for us to be involved with Heart Kids."

That feeling is mutual. The Supercheap Auto whānau are absolute superstars in our eyes – raising funds, spreading awareness, and showing up year after year with full enthusiasm.





Ō MĀTOU KAITAUTOKO

OUR SUPPORTERS

To our incredible supporters Heart Kids NZ is deeply grateful for the steady and heartfelt support we receive from across the motu. From the smallest rural towns to our biggest cities, we are constantly moved by the generosity, compassion, and community spirit shown by people who choose to stand alongside heart kids and their whānau.

Our supporters come from all walks of life – individuals, families, schools, ECEs, sports teams, local clubs, community groups, businesses, corporate partners, and iconic Kiwi brands. Some of you have a personal connection to our cause, while others simply saw the need and chose to help. No matter how you found us, we're so thankful you're here.

You've fundraised in creative, bold, and beautiful ways – running marathons, selling cupcakes, hosting wear red days, organising raffles, shaving your heads, and even plunging into icy pools. You've joined in our national campaigns, raising awareness and vital funds so we can continue supporting families through some of their most challenging times.

Many of you have quietly contributed behind the scenes – offering professional services, donating goods, or simply showing up when a local Taituarā or family needed a hand. Some have championed Heart Kids in your workplaces or rallied your friends and whānau to support us. However you've helped, your kindness has rippled far beyond what you might see.

Every act of support, no matter the size, helps us show heart families that they're not alone.

There is no cure for a childhood heart condition. The journey is lifelong and often unpredictable – full of surgeries, long hospital stays, emotional highs and lows, and big transitions. But what makes a real difference is knowing that others care. That someone understands. That a community is walking alongside you. That's the kind of support you've made possible.

Because of you, we've been able to send care packs during hospital stays, run Murmurs coffee catchups where heart parents connect in their communities, host special events and Heart Kids camps where kids feel seen and safe, and support heart teens and adults as they navigate school, work, and adult life. You've helped us be there after diagnoses, during hospital stays, through recovery, and in heartbreaking moments of grief and loss.

You've helped us wrap around families with practical help, emotional support, and a sense of belonging – through every age, stage, and challenge.

Your belief in our work keeps us going. Every donation, every hour volunteered, every share, every conversation – it all adds up to something powerful. A community built on care, connection, and hope.

Thank you for standing with us. Together, we're stronger. Together, we are Heart Kids NZ.

Heart heroes

Motatapu Challenge

Heart Kids NZ supporter, Sam Edmond, friend of a heart adult, ran the Motatapu Trail Marathon 42.2km. Sam raised a whopping \$13,624 for Heart Kids NZ through his mammoth effort!

Auckland Marathon

Jimmy who came all the way from Australia in support of Heart Kids NZ, blew us away with fundraising \$5,014.60, not to mention his funny social posts. The Auckland Marathon fundraisers contributed a total of \$8,099.80, thanks to a small but mighty group of runners.

Te Araroa Trail

Te Araroa trail fundraiser, Alan, fundraised \$3,400 which he then generously matched himself to make \$7,300! We're so lucky to have incredible fundraisers such as Alan who are committed to raising awareness and funds for HKNZ.

New York City Marathon

Heart adult, Ashley Farrell, completed the New York City Marathon raising \$2,866 for Heart Kids NZ. Ashley reconnected with HKNZ this year, and has been a huge support at a local level with Heroes for Heart Kids in Christchurch and Christmas Gift wrapping. We're so appreciative of Ashley's support.

Catalytic Foundation

A heartfelt thank you to the Catalytic Foundation for including our heart families in their incredible Christmas Shoebox Project. A special thank you to the volunteers - who helped organise, pack, wrap, and deliver the boxes to ensure that heart families were included in this beautiful initiative

Hospital meals

BSH Home Appliances has been an incredible supporter, with their team regularly cooking and donating hundreds of homemade meals for families in Ward 23B.

Good Bitches Baking

A huge thank you to Good Bitches Baking, whose incredible volunteers bake and deliver a weekly box of treats for the 23B Parent Support Group, plus extra boxes each month for the Youth Transplant Clinic at Starship. Their generosity allows us to offer comfort and care that would otherwise be out of reach. Even better, their support extends across the country, helping taituara support heart whānau.



SERVING THE COMMUNITY

In 2024, we were once again humbled by the kindness and commitment shown by our supporters across Aotearoa. From essential grant and trust funding to the ongoing generosity of our corporate partners, from passionate community fundraisers to the everyday heroes who gave goods, services, time, and heart – every contribution made a real difference.

KEY SUPPORTERS

BSH
Bunnings
Corporate Challenge
Embracing Hearts
Glowbox
Paul and Liz Blackwell
Petes Natural
Supercheap Auto
Uplift in Kind
Z Energy “Good in the Hood”

JOIN US

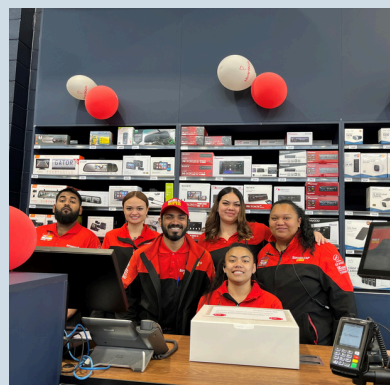
If you are interested in joining our valued team of community or corporate heart heroes, then we would love to hear from you! Contact: fundraising@heartkids.org.nz

TRUSTS AND FOUNDATIONS

ANZ Staff Foundation	Maurice Paykel Charitable Trust
Aotearoa Gaming Trust	Milestone Foundation
Bay Trust	Newman's Own Foundation
Blogg Trust	Nikau Foundation
Blue Sky Community Trust	Norah Howell Charitable Trust
Catalytic Foundation	NZ Community Trust
Central Lakes Trust	North and South Trust
Charities Aid Foundation	Oxford Sports Trust
Christchurch Airport Community Fund	Pub Charity
Christchurch Casinos Charitable Community Trust	Rata Foundation
David Ellison Charitable Trust	Rotorua Trust
Dunedin City Council	Sargood Bequest
DV Bryant Trust	TECT
E B Millton Charitable Trust	Thomas MacCarthy Charitable Trust
Eastern & Central Community Trust	TOI Foundation
Foundation North	Top of the South Community Foundation
Four Winds Foundation	Trillian Trust
Grassroots Trust	Trust House Foundation
JM Thompson Charitable Trust	Trust Waikato
Keith Laugesen Charitable Trust	Waikato WDFK Karamu Trust
Kiwi Gaming Foundation	WEL Energy Trust
Lindsay Foundation	Wellington Children's Foundation
Lion Foundation	Whanganui Community Foundation
Lotteries Community Fund	
LW Nelson Trust	
Mackenzie Charitable Foundation	

DONATE

You can become a regular giver or make a one-off donation into our ASB bank account.
Account name: **Heart Kids NZ**
Account number: **12-3209-0368133-00**
Or online: heartkids.org.nz/donate





Kōrero pono o te manawa

HEART STORY

George



Heart mum, Elaine, shares her journey with George.

George was born on Christmas Eve 2015, 12 hours after his birth he was rushed back to hospital in an ambulance where we got the earth-shattering news that there was something wrong with his heart. To say we were devastated would be putting it mildly, we had just welcomed him into this world and suddenly we were faced with losing him.

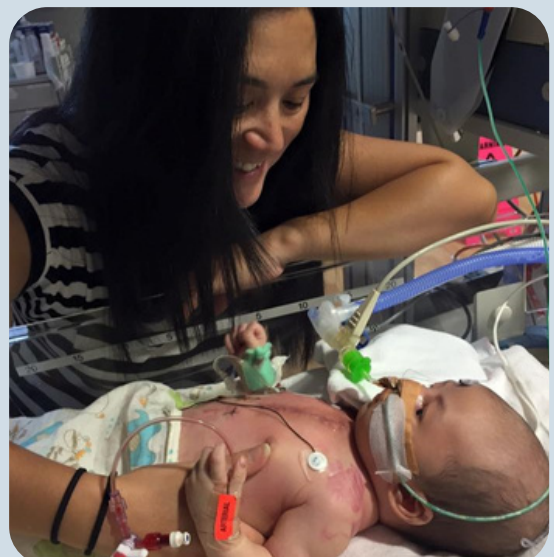
George spent the first few years of his life in and out of Starship Hospital and in a bubble even when he was home.

“Little things like a hospital support worker bringing us a coffee when we were stuck in a hospital room feeling very sleep deprived might seem like a small thing but in that moment, it is everything.”

Catching a cold usually ended up with him back in hospital. Fast forward 9 years, 4 surgeries and 7 cardiac catheters and George is thriving.

He is a fun loving, kind, cheeky kid who loves football and gaming. To see him now you would have no idea of how hard he has had to fight to be running around the football field with his mates.

Sadly, his heart journey is far from over as there will never be a 'last op' for George. He will always need close monitoring and further interventions and surgeries.





Heart Kids came into our lives right at the start when Nana Marie popped into our room on the ward. Since then, they have always been there for us, supporting us in our hard times and cheering us on in our good times.

George loves going to Heart Kids events and meeting other kids with 'special hearts' like him. When he was younger, going to murmurs coffee groups was a highlight as it was a safe space to talk with other parents who 'got it'.

Little things like a hospital support worker bringing us a coffee when we were stuck in a hospital room feeling very sleep deprived might seem like a small thing but in that moment, it is everything.



George loves Little Heart Day, his school gets right behind it and George feels very special that there is a day that celebrates all the heart warriors out there like him.





PRONGO PAEARU, TAHUA 2023–2024

PERFORMANCE AND FINANCIAL STATEMENTS

Financial Summary

Summary Financial Statements for Heart Kids NZ Inc for the year ended 30 November 2024

Statement of Comprehensive Revenue and Expense for the year ended 30 November 2024

	2024	2023
Revenue from Operations and other Income	2,883,021	3,341,899
Total Expenses	3,288,039	3,286,922
Operating surplus/(deficit)	(405,018)	54,977
Finance Income	31,442	25,839
Total Comprehensive Revenue and Expense	(373,576)	80,816

Statement of Changes in Equity for the year ended 30 November 2024

	Special Purpose Reserve	Accumulated Revenue and Expense	Total Equity
Statement of changes in Equity			
2022/2023			
Balance as at 1 December 2022	36,165	1,677,788	1,713,953
Total Comprehensive Revenue and Expense	-	80,816	80,816
Net funds received (spent) for Special Purpose Reserve	239,145	(239,145)	-
Balance as at 30 November 2023	275,310	1,519,459	1,794,769
2023/2024			
Balance as at 1 December 2023	275,310	1,519,459	1,794,769
Total Comprehensive Revenue and Expense	-	(373,576)	(373,576)
Net funds received (spent) for Special Purpose Reserve	(10,093)	10,093	-
Balance as at 30 November 2024	265,217	1,155,976	1,421,193

Statement of Financial Position as at 30 November 2024

	2024	2023
Assets		
Current Assets	1,762,392	2,028,530
Non-Current Assets	49,678	128,713
Total Assets	1,812,070	2,157,243
Liabilities		
Current Liabilities	390,877	362,474
Total Liabilities	390,877	362,474
Net Assets/Equity	1,421,193	1,794,769

Statement of Cash Flows
for the year ended 30 November 2024

	2024	2023
Net Cash inflows/(outflows) from Operating Activities	(315,176)	(46,521)
Net Cash outflows from Investing Activities	(17,907)	(109,030)
Net increase/(decrease) in Cash Equivalents	(333,083)	(155,551)
Cash and Cash Equivalents at the beginning of the year	1,229,233	1,384,784
Cash and Cash Equivalents at the end of the year	896,150	1,229,233

These summary financial statements have been extracted from the full financial statements. They comply with Public Benefit Entity Accounting Standards Reduced Disclosure Regime (PBE Standards RDR) as they relate to summary financial statements. All figures are in NZ\$.

The full financial statements were authorised for issue by the Board on 14 April 2025

The full financial statements have been prepared in accordance with PBE Standards RDR and they comply in full with those Standards.

The summary financial statements do not include all the disclosures provided in the full financial statements and cannot be expected to provide as complete an understanding as provided by the full financial statements.

The full financial statements have been audited and a qualified opinion was expressed over all periods presented in these summary financial statements.

A full set of the audited financial statements is available on our website: heartkids.org.nz (ph. 0800 543 943).



Report of the Independent Auditor on the summary financial statements

To the Members of Heart Kids New Zealand Incorporated

Placeholder – awaiting inclusion



info@heartkids.org.nz



www.heartkids.org.nz



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