

## Born Fighters Campaign

Thank You!

## Ward 23B

Heart Kids Resources

## Cycle Challenge

Cycle for Heart Kids



# HeartKids

[www.heartnz.org.nz](http://www.heartnz.org.nz)



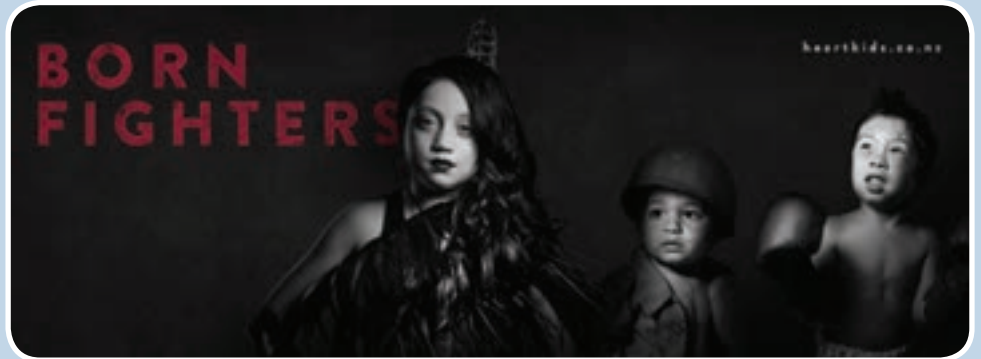


# A Message from Rob

We have just wrapped one of our best Heart Kids awareness campaigns ever, and I would like to extend a very warm thank you to everyone who helped share the word about Heart Kid and CHD, right across the country.

We have received incredibly positive feedback about Born Soldier/Fighter/ Warrior campaign from far and wide. We were on Breakfast TV with Sam Wallace, Corey Anderson and some very special heart kids, and Auckland's Sky Tower was lit up red for a week with the top part flashing like a heartbeat. Westfield malls throughout New Zealand displayed digital posters, and we also had buses and bus shelters covered with our campaign artwork and messages, as well as street posters in our main centres. We had many wonderful collectors throughout New Zealand bucket shaking and helping raise awareness of Heart Kids, and our Branches had displays in malls in their areas. We had over 30 personal Heart Kids families' articles in local papers and magazines, and even made it to the front page of the Herald! All of this activity was to raise the awareness and profile of Heart Kids and CHD, and we are very grateful for the fantastic support from so many to make this great campaign such a success.

We have also been working very closely with the medical team at Starship and our Regional Hospitals to develop and enhance our relationships with these essential partners. From our dedicated Family Support Team at regional Hospital clinics to Starship and Auckland Hospital up to senior levels, the team has been working hard to build these crucial relationships. Together with the leaders of the paediatric cardiac team, we have jointly visited the Minister of Health to lobby for more funding for the National Service so



*Born Fighters campaign*

the Medical team can provide a better service and we're also hoping this will help decrease the surgical cancellations that are very difficult on our families.

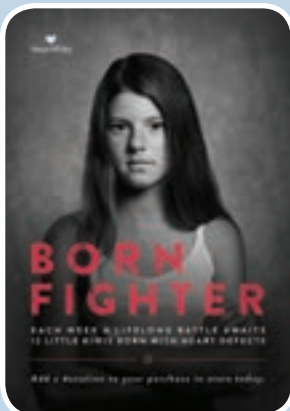
We are collaborating on a nationwide compulsory oximetry testing of all new born babies, with a pilot programme to be undertaken in the Auckland area. This will ultimately save five of our Heart Kids lives a year if undertaken throughout New Zealand.

I am also pleased to report that the Heart Kids Board have made a decision on our new logo. We know that this has been a bit continuous and it has been a lengthy and involved process to ensure we end up with the visual elements which best reflect who we are as an organisation. I am confident that the consultation process that was undertaken as very solid and robust and all feedback - good, bad and indifferent - was given to the Board to

consider as part of the decision process. I am hopeful that when the new logo is announced, once the final legal steps have been completed, that we will all join together to support our organisation and use this logo to keep raising our profile.

Lastly this month we will have our first conference in five years. By the time you receive this Heartline, we will have had the pleasure of a full-on weekend of learning, sharing and connecting with heart kids, parents, medical specialists and supporters from all over the country. I am really looking forward to meeting more of our members, and reporting back to you on the conference in our next edition of Heartline.

**Rob Lutter, CEO**



*Born Fighter  
Samara McKenzie*



*Shaking a bucket for  
Heart Kids*



*Digital poster in a  
Westfield mall*



*Heart Kids Canterbury street appeal*



*An inspiring speech by Andrew Fiu*



*Founding member Linda Davies presenting Honorary Life Membership to Nana Marie and Dida Joe*



*Delegates chilling out in the AB locker room*

## National Conference

After months and months of preparation and hard work, the much anticipated National Conference finally took place on the 26th & 27th of September at Eden Park Function Centre in Auckland. We were pleased to be able to host over 150 delegates including medical and health professionals, heart teens, heart adults and heart parents over the two days at this event.

The Conference, the largest gathering of our constituents since the One Heart conference in 2010, was significant to Heart Kids. It provided a very special opportunity for our members from all over the country to come together, connect with, listen and learn from the team from Paediatric and Congenital Cardiology Services outside hospital setting.

It was wonderful to see our members actively engaging in conversations, participating in discussions and sharing knowledge and experience with one another. The conference provided a memorable, enriching experience for the participants and it was reported that they returned home with a sense of empowerment, renewed energy and commitment to caring for and supporting our Born Fighters.

We were extremely grateful to all our speakers for giving their time over the weekend to come and share their knowledge and expertise with our members. We would also like to thank BlueSky Trust, First Sovereign Trust and Mt Wellington Foundation for funding attendance of representatives from Heart Kids, Paediatric and Congenital Cardiac Services, and collaborative organisations. A special thank you to Eden Park Function Centre for the spectacular venue and the waiver of room hire. Also, huge thanks to our volunteer Stephen Edmonds for his time, input and involvement in the planning and preparation of the Conference. Best of luck to everyone and we hope to see you again at another Heart Kids event.

### Mark your diary

9 October	Heart Stopper Canterbury
17 October	Heart Stopper Wellington
18 October	Heart Stopper Manawatu
31 October	Heart Stopper South Auckland
28 November	Contact Lake Taupo Cycle Challenge
28 November	5km Kids Heart Ride
18-22 Jan 2016	Camp Brave Hearts

## National Family Support Training

On the Friday prior to the Conference, we've had the wonderful opportunity to bring together our family support workers from across the country for the National Family Support Training in Auckland. We've had a jam-packed agenda that covered many different aspects of family support such as professional boundaries; relationship with health professionals and community agencies; prenatal and bereaved family support; Murmurs Coffee Groups guidelines and promotion; rheumatic heart disease updates and support; and self-care and maximising supervision.

It is clear that the training, which was about celebrating, sharing and improving best professional practice, had certainly helped to further develop our team's professionalism and expertise in delivering timely and quality services to our members. Our Family Support Workers left the training with new knowledge and a renewed sense of focus, confidence, energy and empowerment to continue the vital support they are providing to heart kids and heart families. Well done team!

## A trip down memory lane

This image of heart kids was taken at Green Lane Hospital over half a century ago, in 1964. Mrs. D.M. Sale, the children heart unit's teacher known for her outstanding human touch, was with the kids on the steps of the classroom that was part of the unit. An inspector of schools criticised her failure to cover the curriculum and get sufficient work out of her very sick pupils. He withdrew his criticism when, not long afterwards, he fell victim to a heart attack himself! We are grateful to A.S. Collins for sharing with us this special piece of Heart Kids history. It put into perspective the journey heart kids like A.S. Collins and their families had to go through back then.



# Ages and Stages Questionnaire Explained

The Ages and Stages Questionnaire (ASQ) is a screening tool that may identify children at risk for developmental delay. Developmental and behavioural problems are a common issue for children admitted to Starship Children's Hospital. Whilst 2.5% of all children have developmental delay, and a further 7.5% have concerns requiring ongoing monitoring, these percentages are significantly greater in children referred to a Children's Hospital.

Currently, identification of developmental concerns relies on parental concern or a clinician including questions regarding developmental status in their clinical assessment. International research suggests this practice only identifies approximately 30% of children with developmental problems. The use of a standardised developmental screening tool increases the pick-up rate of developmental delay to almost 80%, allowing earlier identification and intervention thus improving developmental and social outcomes.

A pilot study was introduced in the Paediatric and Congenital Cardiology Service (PCCS) in May 2014. It aims to establish feasibility and gather preliminary data to support funding for the long-term implementation of the ASQ in cardiac services. The aim is to provide routine developmental screening for all children (1 month – 5 years) admitted. The earlier the identification, the earlier the intervention.

## Why was the ASQ chosen as a screening tool?

- Parent lead
- User friendly
- Designed to be playful, fun, interactive and linked to children's milestones
- Affordable, quick and easily completed
- Few resources are needed
- High rates of reliability, validity, and accuracy
- Culturally appropriate

As the Hospital Play Specialists on the ward, Denise and Lindy have the educational background to assist parents with their child development questions. Denise also has a background as an Early Intervention Teacher with the Ministry of Education, and Lindy was an Education Support worker in the community.

We recognise parents as children's primary educators and caregivers. Parents inevitably know their child best, and this screening tool also celebrates the developmental domains that children are meeting as well as the areas that need monitoring or referring to specialist services.

## The ASQ

Is a series of 21 questionnaires for children (1 month – 5 years). These questionnaires cover age related questions in 5 developmental domains:

- COMMUNICATION - verbal and non-verbal communication skills
- GROSS MOTOR - children's use and co-ordination of their arms and legs
- FINE MOTOR –children's use and co-ordination of their hands and fingers
- PROBLEM SOLVING – children's ability to work out cause and effect
- PERSONAL-SOCIAL – children's self-help skills and interactions with others.

For each age group and domain there are activity sheets to assist parents if required. These activity ideas are easy and enjoyable.

On admission the Nurses hand out this questionnaire to the parent. Once completed Denise and Lindy mark the questionnaire. We then discuss the results with the parents/caregivers/Whanau and the results are recorded on the PCCS database.

For those children whose results indicate that further assessment is required, this is stated in the discharge letter forwarded to the child's Paediatrician/Primary Health Care Provider.

This initiative may assist in addressing the well documented presence of developmental delay in the complex congenital heart disease children under our care.

Ana Kennedy has been instrumental in introducing this pilot study of the Ages and Stages Questionnaire (ASQ) to the PCCS in May 2014.

**Ana Kennedy, Nurse Practitioner,**

**Denise Skeen and Lindy Slater Hospital Play Specialists 23B**

## Practical resources for families on Ward 23B

We are extremely grateful to Pub Charity Ltd for a grant to purchase practical supplies and educational resources for families on Ward 23B at Starship. These include books, Skylight resources, toys, blankets, emergency toiletries, petrol and grocery vouchers, and a chest freezer to store meals cooked by our corporate supporters for parents keeping vigil at the bedside of their heart child.

Having a child in hospital is a stressful event for parents and no family can ever be fully prepared, especially for emergency admissions and unexpected long hospital stays. These practical and educational resources are vital to the overall care and wellbeing of our hospital-bound Born Fighters and their families. Thanks again to Pub Charity Ltd for the grant that helps us to provide the support our heart kids and their families need to make their hospital stay a bit easier.



# Born Warrior

## Kayla Salter

Nothing could dull the sparkle of Kayla Salter, a fun-loving 10-year-old who always wears a big smile on her face. Her love of acting has brought so much joy and laughter to her family and those surrounding her. It's hard to think this feisty little girl is living with an incurable heart condition that required an open-heart surgery to save her life.

Kayla was born in March 2005 at 31 weeks weighing 3lbs. Two weeks after she was born, we were called into the Neo Natal Unit to talk with the doctors. That day was just a big blur, yet I still remember the heart-breaking feeling when our whole world changed.

We were told that Kayla's heart did not function as it should be. She was diagnosed with Tetralogy of Fallot, a congenital heart condition consisting of four anomalies requiring open-heart surgery.

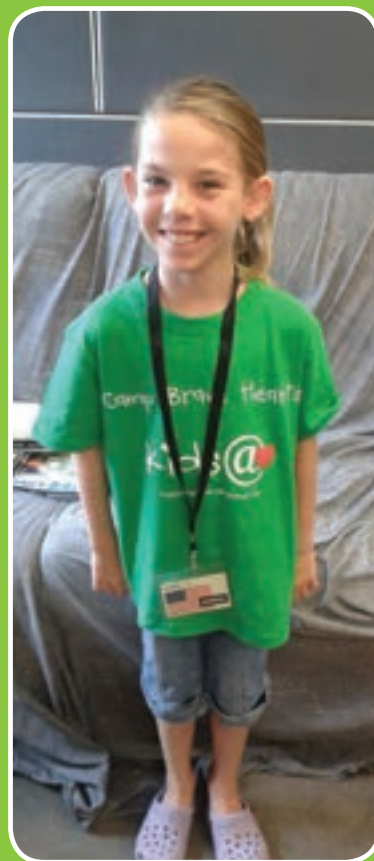
That day we were also put in touch with a family support worker from Heart Kids, who were invaluable at our time of need. They gave us information on what to expect and basically held our hand through the journey that is now our life.

In September 2005 Kayla had an open-heart surgery at six months old. Since then, she has been thrown a lot of hurdles to try get over. In 2012 she was diagnosed with a growth hormone deficiency and started growth hormones in 2013. She also has Sub Pulmonary Stenosis which is being checked by cardiologists every 6 months.

Kayla and our family have been lucky enough to still have the support of Heart Kids with Kayla going to Camp Brave Hearts this year and also lots of family events.

We have tried to let Kayla be a 'normal' 10-year-old and this year she decided to show off and came third in school cross country. We are very proud of how far she has come and not letting a heart condition slow her down!

**Vikki Farley**  
Mum



Donate online at:  
[www.heartkids.co.nz](http://www.heartkids.co.nz)

## Family Support new face



A belated welcome to Prue Burbidge, the new Family Support Worker for Heart Kids Wellington. Prue brought with her 30 years of experience in counselling, parenting, behavioural support and therapy for children and families. She spent the last 10 years working with a charitable trust helping families with children with autism or intellectual impairment.

Prue loves meeting people and she finds it a privilege to work alongside families providing the support they need. In Prue's leisure time, you'll find her gardening or walking on the beach along the Kapiti Coast. Prue is excited about her new role and is looking forward to getting to know more heart kids and families at Murmurs coffee group, family events and Starship clinics.

She can be reached on 021 508 502 / 04 212 5232 or by email at [Wellington.FSW@heartnz.org.nz](mailto:Wellington.FSW@heartnz.org.nz).



Not long to go until the next four Heart Stopper events held in Christchurch, Wellington, Palmerston North & Manukau on the 9th, 17th, 18th & 31st of October respectively! The branches are accepting team and individual registrations so sign up now on the event's website and get ready to show off your craziest costume, take an icy dip and have a good laugh on the day. There will be fantastic PRIZES for Best Team Costume,

Top Fundraiser and Team Spirit for each event. Be sure to ask everyone you know to sponsor your brave act.

If an icy dip is not for you, you can show your support of the plungers' effort by making a donation through their fundraising page on the event's website at [www.heartstopper.org.nz](http://www.heartstopper.org.nz)

**If you'd like any information on the Heart Stopper Challenges email us on [events@heartnz.org.nz](mailto:events@heartnz.org.nz). We'd love to hear from you!**

**SUPERCHEAP  
AUTO**



*Supercheap Auto Mill Street store came third in the chain's fundraising campaign in May. Beth, Kirk & little Sierra from Heart Kids Waikato presenting a certificate to the amazing team for their fantastic effort.*

We were blown away by the phenomenal success of another 'Add \$1 at the till' campaign in May. Huge thanks to all of you for your donations that help Heart Kids to provide vital support to our members throughout the country. Special thanks go to the Head Office team and the regional managers of Supercheap Auto. Their passion, motivation and involvement are integral to the continued success of the campaign and we are stoked to receive their unwavering support and commitment over the years. **The November campaign is just around the corner.** If you need any auto parts and accessories, make sure to pop in to your nearest Supercheap Auto store to check out their amazing range of products.



*Supercheap Auto store in Palmerston North came second in the chain's fundraising campaign in May. Our lovely heart family Michelle Fagan-Burns with little Mitchell visited the team to say thank you on behalf of Heart Kids.*



# Cycle Challenge

Saturday 28 November, Lake Taupo

HUGE Congratulations to the wonderful team at Contact Lake Taupo Cycle Challenge! This premier event was crowned the Best New Zealand Owned Major Event at the 2015 New Zealand Association of Event Professionals (NZAEP) Event Awards. It's a well-deserved recognition of the hard work, professionalism and passion of the entire Cycle Challenge event team. We are proud of the team and super proud to be the official charity of the Cycle Challenge.

## Cycle for Heart Kids

As the charity of choice for the event, we are given the opportunity to promote Heart Kids to all participants, and encourage them to join us in supporting our born fighters as they take on their own lifelong challenges. All you have to do, once you have signed up for the event, is to create an online fundraising page at <https://www.everydayhero.co.nz/event/cycleforheartkids2015>.

Every dollar you raise as you train, cycle, eat, breathe and sleep the upcoming Cycle Challenge assists Heart Kids NZ to provide support services, activities and programmes for heart kids around the country. We are looking forward to having you as part of the Cycle for Heart Kids team for 2015!

## Kids Heart Ride

Also, your kids can be part of this prestigious adult cycling event by entering the Kids Heart Ride. We have 39 complimentary entries up for grabs for heart kids and their siblings aged 10 years or under. It's going to be a fun-filled day as we ride the 5km round the lake edge as a group and cross the finish line to lots of cheers. We will have a special prize draw for our Kids Heart Riders at the prize giving followed by a BBQ. To sign up, please email us at [heartkidsevents@gmail.com](mailto:heartkidsevents@gmail.com) and we will be in touch with all the details.

One of the riders taking part in the Kids Heart Ride is five-year-old Talia Faith Griessel from Christchurch. Talia is a very special girl with a big heart. She has wanted to do the Kids Heart Ride ever since watching her dad and brother doing the Cycle Challenge. She is determined to take on the challenge this year so she can help



**HeartKids**

**RISE FOR OUR BORN FIGHTERS**

Marc is 1 of the 12 little kiwis born every week with a heart defect. You can ride for him at the Contact Lake Taupo Cycle Challenge as he may never be able to.

**SIGN UP TO CYCLE FOR HEART KIDS** ➔



*Talia and her mum Anneliese (left) popping in to the Heart Kids National Office to say hi.*

heart kids to have good lives and fun times. Like many of our heart kids, Talia is a regular at Starship as her bones need special care. She had an operation on her knees recently and can only walk with the help of crutches but that doesn't stop her from getting on her specialised bike to do a bit of training with her dad. Talia is truly an inspiration and we are proud of her!

Be sure to check out Talia's story on her fundraising page at <https://cycleforheartkids2015.everydayhero.com/nz/talia-faith> and give her the support she needs to complete the ride.

She would love to have you sponsoring her effort!

# Thank You

Grants from trusts and foundations provide a vital source of funds for our organisation as we are not government funded and we rely solely on voluntary donations to fund all our services. This year, we have received grants from a number of trusts and grant-giving bodies including BlueSky Community Trust, COGS Far North, COGS Whangarei/Kaipara, COGS Coastal Otago/Waitaki, COGS Christchurch City/Banks Peninsula, First Sovereign Trust, Four Winds Foundation, Infinity Foundation, JM Thomson Trust, Mt Wellington Foundation, Trillian Trust and Youthtown. A heartfelt thank you to these organisations for their support and generous gifts that continue to make our work possible.

## Good in the Hood

A special thank you to Z for their amazing support of our local branches including Heart Kids Auckland, Heart Kids Central Otago, Heart Kids Hawkes Bay, Heart Kids Manawatu, Heart Kids Napier, Heart Kids Waikato and Heart Kids Wellington. These branches were chosen by a number of local Z stations as one of four community groups to receive funding from their Good in the Hood community programme.

We were super excited for Heart Kids Waikato to receive an additional \$13,000 through the Good in the Hood - Supercharger. The Supercharger funds allowed Heart Kids Waikato to send local members to the National Conference in Auckland, help with petrol costs for families traveling to Auckland for their heart child's treatment, and provide other practical support to local heart families. Well done teams!



Robyn Wickenden (third right) from Heart Kids Auckland with Z Lakeside staff and other Good in the Hood funding recipients



An awesome gift from Z to Heart Kids Waikato

## Yes, I want to make a donation to Heart Kids NZ

Complete and post this form to Heart Kids NZ, PO Box 108 034, Symonds Street, Auckland 1150.  
For further information on donating, please email: [giving@heartnz.org.nz](mailto:giving@heartnz.org.nz) or call 0800 543 943.

Oct 2015

(Miss/Ms/Mrs/Mr) \_\_\_\_\_ Name \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

Postal Address: \_\_\_\_\_

My cheque made payable to Heart Kids NZ is enclosed: ☐ \$150 ☐ \$75 ☐ \$30 ☐ \$ \_\_\_\_\_

☐ Visa ☐ Mastercard Card no.

Cardholder's name: \_\_\_\_\_ Expiry date:     Signature: \_\_\_\_\_

Donations can also be made directly to the Heart Kids NZ bank account ASB #12-3209-0368133-00

Please contact me with more information about ☐ becoming a regular donor ☐ leaving a bequest to Heart Kids NZ

☐ I would like to receive communications via email. Please make sure to fill out the email field above.

☐ I would like to unsubscribe from your newsletter mailing list.