

Children's Heartbeat Trust:



CHILDREN'S
HEARTBEAT
TRUST

Northern Ireland's
Children's Heart Charity
Charity no: NIC 102410

The Heart of What We Do

Making a big
difference for
little hearts



The Need



Our Mission

Children's Heartbeat Trust has been dedicated to supporting children, young people, and their families affected by heart disease in Northern Ireland since 1984. We provide practical support, emotional care and financial help to children and young people living with heart disease, as well as their families.

The need to help little hearts in Northern Ireland is vast.

Imagine watching the screen during your 20-week scan, captivated by tiny toes and the gentle flicker of a heartbeat. Or feeling the overwhelming rush as your newborn wraps their fingers around yours for the very first time. Now imagine that same moment but instead, you're being told your baby has a serious heart defect. That they'll need surgery within days or months of being born and that their future is uncertain.

This is the reality for four families, on average, each week in Northern Ireland.

Congenital Heart Disease (CHD) is the most common heart condition babies are born with in Europe, affecting around 1 in every 100 newborns in the UK. (Source: NHS UK)

In Northern Ireland, around 4,000 children and young people live with congenital heart disease and Children's Heartbeat Trust exists to empower and support them when needed.

Thanks to advances in medical care, survival rates for children with congenital heart disease have improved significantly, however the impact of this life-limiting condition is profound. The emotional and mental scars often remain. This impact is frequently overlooked and sadly, progress in health and wellbeing support hasn't kept pace with medical breakthroughs.

Congenital Heart Disease is not just a medical condition - it's an emotional journey that touches every aspect of a young person's life.

For children and their families, the challenges go far beyond surgery and hospital stays. Without the right support systems in place, many face overwhelming stress, anxiety and a deep sense of isolation.

The Need

Every year, around

200

babies in NI are born
with heart disease

There are

20

distinct types of congenital
heart disease, each
requiring specialised
care and treatment.

Around

4,000

children and young people
live with congenital heart
disease in NI.



The Need



The Foundation of Children's Heartbeat Trust

Children's Heartbeat Trust was founded by families who came together to support each other after they experienced firsthand how little emotional support was available for parents of children with heart disease.

The cardiology team at Children's Heart Centre situated in the Royal Belfast Hospital for Sick Children has been a global leader in cardiac care and understands how important it is to provide emotional and practical support for parents alongside the best medical treatment.

Children's Heartbeat Trust offers emotional support to parents, children and siblings because we believe that families should not just survive but thrive. Research, including studies from the Congenital Heart disease Intervention Programme (CHIP), shows that families who receive this kind of support see better outcomes in their children, proving the critical need for emotional and practical care.

Our Vision for the Future

Children's Heartbeat Trust is committed to growing a wide range of support services, that are shaped by research, evidence and what families need most. We work together with children, parents and clinical teams to create these services, making sure that families can access high quality medical, practical and emotional support and are fully supported at every stage of their journey with heart disease.

Without Children's Heartbeat Trust, there would be no tailored support for families, from pregnancy through to post-treatment and beyond, leaving them to navigate the challenges of heart disease on their own.

Children's Heartbeat Trust is the essential lifeline providing this crucial support.

For over 40 years, Children's Heartbeat Trust has been dedicated to supporting children and young people living with heart disease and their entire family. We recognise that early intervention, starting from the antenatal phase and continuing throughout a child's life, leads to long-term benefits for all the family. Our services complement the world-leading care provided by the clinical teams and are valued by them, ensuring families receive holistic, wraparound support.

Our services have expanded significantly since becoming a registered charity in 2015, all designed to meet the evolving needs of families. Our work is informed by research, evidence, and direct input from families and clinical teams who understand what is needed most.

We are the only charity in Northern Ireland providing support to these families at every stage of their journey.

Supporting Heart Families

Our Core Services

Emotional Support in Hospital and Beyond

A child's heart diagnosis can turn a family's world upside down. That's why our dedicated family support team make regular hospital visits to listen, guide and help parents, and children, cope with the emotional impact from the very start. We provide free, professional counselling and practical coping tools to ease anxiety and stress. Our team also offers tailored Play & Prepare sessions delivered at home or in hospital to help young children understand and feel ready for their upcoming surgeries.



86%

of families reported that our emotional support significantly reduced anxiety.

Financial Support for Families

Caring for a child with heart disease often means long hospital stays, regular travel and time away from work, all of which can place a heavy financial strain on families. Children's Heartbeat Trust offers financial support to help ease this pressure, so parents can concentrate on what matters most: their child's health and recovery.



98%

of parents report that our financial support significantly reduced their stress.



Supporting Heart Families

Our Core Services



Accommodation for parents

When families live far from the hospital, being close to their child during treatment is essential. Our on-site accommodation at the Royal Belfast Hospital for Sick Children offers parents a safe, comfortable place to stay just steps away from the ward, giving them the space to rest, recharge and be there for their child every step of the way.



In 2024,
124

families benefited
from our parent
accommodation.

Medical Equipment

We help provide extra equipment and resources to make life a little easier for families and enhance patient care. This includes things like home monitoring equipment, so children do not need to travel to hospital as often and comfortable armchairs for parents on the ward. These key resources make for better care and support to both children and their families.



**"Making
life a little easier
for families and
patients."**

Paediatric Cardiology
Nurse

Supporting Heart Families

Our Core Services

Youth Support

Thanks to better treatments, more young people with heart conditions are growing up and living full lives. But living with congenital heart disease as a teenager or young adult comes with its own challenges and we're here to help.

Our Youth Council is made up of young people who live with heart conditions themselves, so they understand what it's really like. They help design the support we offer, which includes peer meetups, mental health workshops, one-to-one chats, counselling and guidance for when they move onto adult cardiology care.

We're proud to run our Young Hearts youth programme across Northern Ireland, designed to ensure accessibility for young people living with heart disease. These four programmes are specially tailored for young people aged 7 to 21 offering fun, friendship, and practical support to help them navigate life's challenges. Young Hearts equips young people with the knowledge and tools they need to make informed decisions and provide them with the support network they need.



100%
mental health
improvement for young
people after
our Summer
Residential.



Supporting Heart Families

Our Core Services

Sibling Support

We provide age-appropriate support for siblings aged 10-13, who feel 'forgotten' when a brother or sister is seriously ill. These children can feel guilt, fear, resentment, or even grief, and it's important they're not left to cope alone. Research shows that siblings of children with heart disease can be more deeply affected than those with siblings facing other serious conditions. Our programme gives opportunities to connect with others, take part in fun and educational workshops to help them understand and manage these emotions early on and support their long-term wellbeing for the future.



"It's important siblings are not left to cope alone."

Parent

Local Family Support Groups

We run local support groups and events across Northern Ireland, giving heart families the chance to connect with others who understand. These relaxed, friendly gatherings are for the whole family - parents, heart children and siblings, offering a space to connect, have fun and feel supported, all close to home.



98%

of families reported that these events provided quality family time.

71%

reported that events helped them grow their support networks.



Supporting Heart Families

Our Core Services

Bereavement Support

Sadly, not every child with congenital heart disease survives, even with the best care. Our bereavement support is shaped by parents who have experienced this heartbreaking loss themselves, so they truly understand.

We offer a safe and compassionate space for families to grieve, remember and celebrate their child. Through special memory events, supportive gatherings, and personalised guidance, families can connect with others on the complex grief journey. We also provide helpful information resources to support siblings and other children in the family to help explain loss in a way they can understand.



100%

of bereaved parents said the greatest benefit was being with people who understood their grief.

80%

of parents said it gave them a strong sense of belonging.

80%

said it reduced negative feelings.

NI's Children's Ambulance

We proudly commissioned and funded Northern Ireland's first and only Children's Ambulance to help ease the stress for heart families travelling to Dublin for surgery or treatment. The ambulance provides a welcoming, child friendly and comforting space in which to travel at a time when anxiety is often at an all-time high.

When it's not being used for cardiac services, it's available to support any child in Northern Ireland who needs specialist transport.



Over

370

trips were made by the bespoke ambulance from Jan 2023 – Jan 2025



Supporting Heart Families

Our Core Services

Advocacy and Research

We are a trusted voice for heart families. As part of the All-Island Congenital Heart Disease Network Board, we lead the Family Engagement Group making sure families are heard and represented at every level. We also Co-Chair the NI Children's Health Coalition, working to improve the quality of health services and holistic support for children, young people and their families in Northern Ireland.



In 2025 we are supporting

7

research projects through QUB, UU and the All Island Network for Paediatric Cardiology.

"We make sure families are represented at every level."

Joanne McCallister,
Chief Executive



Our Impact

What Our Families Say



"Best thing I've done in ages, I love my friends at home but it's nice to not have to sit and explain why I can't do some things. Everyone was really easy to get on with all weekend, it was cool getting to mess about with the leaders too. You see them in the hospital and think they're all serious because they always have to tell us stuff about medicine and all but they're really not."

Youth Programme participant,
age 14

"We didn't expect the help we received so it was a very pleasant surprise during such difficult times. We received financial support which helped with the cost of travelling and staying at hospital but also knowing that someone reached out to us and took our family under their wings meant we didn't feel like we are completely alone in this situation and there are people willing to help if we need it. Having that safety net positively impacted our mental health. The impact was huge. From when I first heard about my child's diagnosis to the fear of the unknown when my baby was born, Children's Heartbeat Trust helped me so much. Before our journey I'd never even heard of the charity, now I am a huge supporter. They helped me feel safe."

Parent

"CHT STARS (bereavement support programme) has been such a massive help to us and we can't thank Children's Heartbeat Trust enough for that. We truly appreciate all the care and kindness that you have put into keeping our little one's memory alive and introducing us to other parents who understand how important that is."

Bereaved Parent



Our Impact

What Our Families Say



"Bringing other heart families together is invaluable, it's great support, as a CHD mum I'm always anxious about taking my son out but when outings are organised by the Children's Heartbeat Trust I'm a lot more relaxed about attending as I know other families with CHD children will be attending and it feels ok to do so. I don't have to explain why he's tired and he's not as self-conscious about his feeding tube because he sees other kids with it. He doesn't feel different, and we are both so much more relaxed."

Parent speaking about our Family Events



Our Impact

What Our Families Say

Discover the full impact of our work and hear real stories through our [Annual Impact Report](#) and our support service [podcast](#)...



The Heart Heroes Podcast



Visit our
YouTube page



YouTube handle:
[@childrensheartbeattrust](#)



SCAN HERE



Visit our
Spotify page



Search on Spotify:
[The Heart Heroes Podcast](#)



SCAN HERE

Impact Report

View our [Annual Impact Report](#)
2023-2024

Visit:

www.tinyurl.com/CHTImpactReport23-24

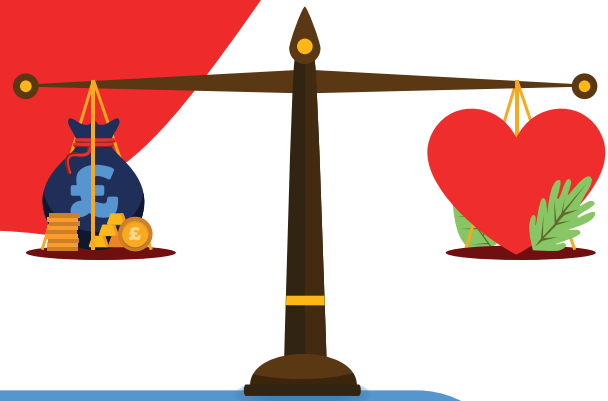


SCAN HERE



Our Impact

Social Impact



For every **£1** invested in Children's Heartbeat Trust, **£6.22** of social and economic value is returned.

- Understanding the social and economic value of our services is crucial for our development and growth. However, it can be challenging to measure and evidence.
- Children's Heartbeat Trust appointed the independent services of the Rose Regeneration to identify a monetary value that represented the impact of its support services over a 12-month period.
- The Rose Regeneration used the Social Value Engine, which is accredited by Social Value International, a global standard setter of social value measurement.

Over 12 months, **£1,644,398.59** of social value was generated in delivering “**Good Health and Wellbeing**”, a key category within the Social Value Engine that is aligned with the **United Nations Sustainable Development Goals**.

Reduced anxiety, stress and isolation

Increased emotional support

Enhanced ability to thrive

Reduced caregiver burnout

Empowered young people

Smooth transition to adult services

Decreased financial strain

Greater understanding of individual conditions

Hope

Our Impact

Social Impact



Examples of support delivered over the 12-month period that generated the social values...



270 children received emotional support from our team throughout their hospital stays.



193 families received financial support.



135 parents benefited from short break respite stays with their children.



50 support referrals from the hospital for parents receiving antenatal diagnosis were fulfilled.



145 children attended family days with their parents.



20 pieces of medical equipment were purchased and donated to the hospital to enable families to self-test at home, avoiding missed school days and missed workdays.



75 parents attended specialist bereavement services.



Rose Regeneration
report into Children's
Heartbeat Trust social
impact



Your Support Can Make a Lifelong Difference

Every donation to Children's Heartbeat Trust directly impacts the lives of children with heart disease and their families. From providing financial relief to offering emotional support, your donation ensures that families are not alone on their heart journey.

£2,500 could support ten families with financial assistance when travelling outside of NI for their child's live saving heart surgery.

£1,000 could support our tailored bereavement programme STARS, for parents who have lost a child to heart disease.

£500 could help fund local family support events across Northern Ireland, bringing families together for peer support.

£300 could pay for specialist home monitoring equipment, meaning a child would not have to travel to hospital.

£100 could provide a Music Therapy session in hospital, helping decrease anxiety for children and their parents.

£72 could facilitate a two hour 'Play & Prepare' session, by our trained Family Support Workers to help a child prepare for heart surgery, in hospital or in the comfort of their own home.

£70 could provide an emotional support session to young patients or parents on the ward, lending a listening ear, helping alleviate anxiety and provide coping techniques.

£64 could provide a support visit from our Family Support Workers after a child has been discharged from hospital, helping reduce loneliness and fear.

For every £1 donated 75p goes directly to our support services for heart heroes, 22p to help raise the next £1 and 3p to ensure we are governed safely.

With your help, we can continue providing essential services, advocating for families, and ensuring every child with heart disease in Northern Ireland has the opportunity to live a long, healthy, and fulfilling life.

Join us in our mission to make a big difference for little hearts.

For more information on how to get involved or donate, visit childrensheartbeattrust.org

Stay engaged and follow us to learn more:

 Instagram: [childrensheartbeattrust](https://www.instagram.com/childrensheartbeattrust)

 Facebook: [childrens.h.trust](https://www.facebook.com/childrens.h.trust)

 LinkedIn: [children-s-heartbeat-trust](https://www.linkedin.com/company/children-s-heartbeat-trust)

 X: [@Chldns_Hrtbeat](https://twitter.com/Chldns_Hrtbeat)

 YouTube: [@childrensheartbeattrust](https://www.youtube.com/@childrensheartbeattrust)

 Spotify: Children's Heartbeat Trust

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